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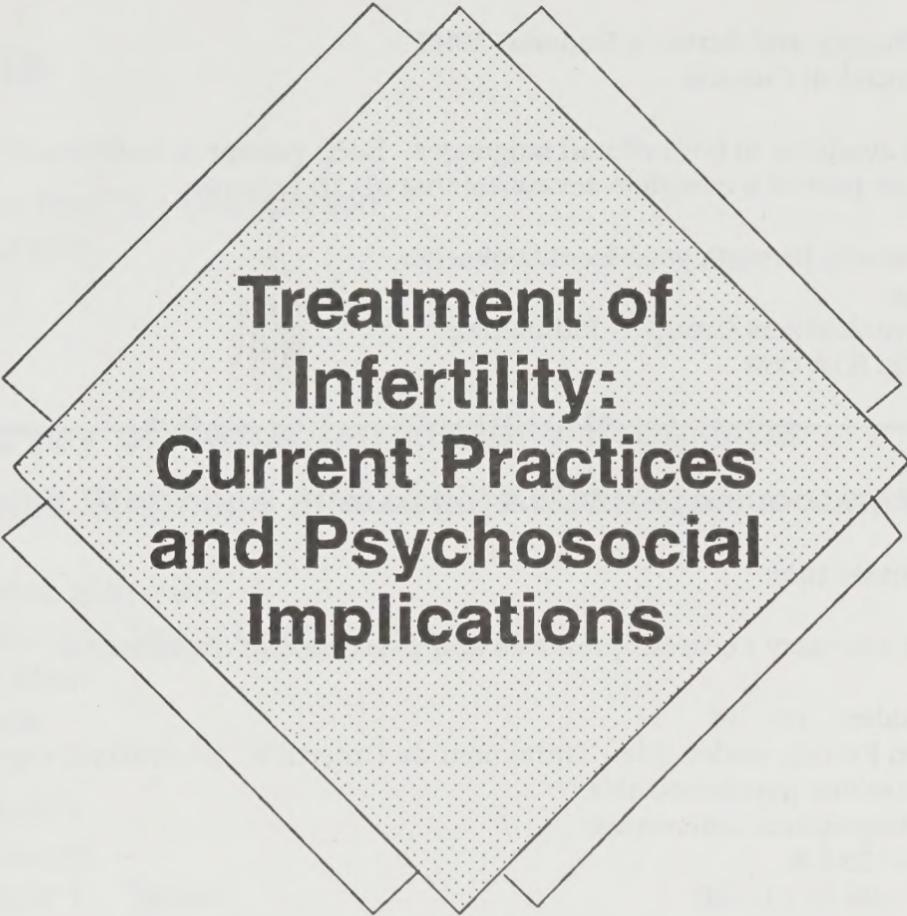
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Research Studies of the
Royal Commission on
New Reproductive Technologies





**Treatment of
Infertility:
Current Practices
and Psychosocial
Implications**

Volume 10 of the
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Royal Commission on
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Thomas Stephens and Janice McLean

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An Evaluation of Canadian Fertility Clinics: The Patients' Perspective

SPR Associates Inc.

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John Collins, Elizabeth Burrows, and Andrew Willan

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**Critical Analysis and Review of the Literature on
the Psychosocial Implications of Infertility
Treatment**

Elizabeth Savard Muir

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Preface from the Chairperson



As Canadians living in the last decade of the twentieth century, we face unprecedented choices about procreation. Our responses to those choices — as individuals and as a society — say much about what we value and what our priorities are. Some technologies, such as those for assisted reproduction, are unlikely to become a common means of having a family — although the number of children born as a result of these techniques is greater than the number of infants placed for adoption in Canada. Others, such as ultrasound during pregnancy, are already generally accepted, and half of all pregnant women aged 35 and over undergo prenatal diagnostic procedures. Still other technologies, such as fetal tissue research, have little to do with reproduction as such, but may be of benefit to people suffering from diseases such as Parkinson's; they raise important ethical issues in the use and handling of reproductive tissues.

It is clear that opportunities for technological intervention raise issues that affect all of society; in addition, access to the technologies depends on the existence of public structures and policies to provide them. The values and priorities of society, as expressed through its institutions, laws, and funding arrangements, will affect individual options and choices.

As Canadians became more aware of these technologies throughout the 1980s, there was a growing awareness that there was an unacceptably large gap between the rapid pace of technological change and the policy development needed to guide decisions about whether and how to use such powerful technologies. There was also a realization of how little reliable information was available to make the needed policy decisions. In addition, many of the attitudes and assumptions underlying the way in which technologies were being developed and made available did not reflect the profound changes that have been transforming Canada in recent decades. Individual cases were being dealt with in isolation, and often in the absence of informed social consensus. At the same time, Canadians were looking

more critically at the role of science and technology in their lives in general, becoming more aware of their limited capacity to solve society's problems.

These concerns came together in the creation of the Royal Commission on New Reproductive Technologies. The Commission was established by the federal government in October 1989, with a wide-ranging and complex mandate. It is important to understand that the Commission was asked to consider the technologies' impact not only on society, but also on specific groups in society, particularly women and children. It was asked to consider not only the technologies' scientific and medical aspects, but also their ethical, legal, social, economic, and health implications. Its mandate was extensive, as it was directed to examine not only current developments in the area of new reproductive technologies, but also potential ones; not only techniques related to assisted conception, but also those of prenatal diagnosis; not only the condition of infertility, but also its causes and prevention; not only applications of technology, but also research, particularly embryo and fetal tissue research.

The appointment of a Royal Commission provided an opportunity to collect much-needed information, to foster public awareness and public debate, and to provide a principled framework for Canadian public policy on the use or restriction of these technologies.

The Commission set three broad goals for its work: to provide direction for public policy by making sound, practical, and principled recommendations; to leave a legacy of increased knowledge to benefit Canadian and international experience with new reproductive technologies; and to enhance public awareness and understanding of the issues surrounding new reproductive technologies to facilitate public participation in determining the future of the technologies and their place in Canadian society.

To fulfil these goals, the Commission held extensive public consultations, including private sessions for people with personal experiences of the technologies that they did not want to discuss in a public forum, and it developed an interdisciplinary research program to ensure that its recommendations would be informed by rigorous and wide-ranging research. In fact, the Commission published some of that research in advance of the Final Report to assist those working in the field of reproductive health and new reproductive technologies and to help inform the public.

The results of the research program are presented in these volumes. In all, the Commission developed and gathered an enormous body of information and analysis on which to base its recommendations, much of it available in Canada for the first time. This solid base of research findings helped to clarify the issues and produce practical and useful recommendations based on reliable data about the reality of the situation, not on speculation.

The Commission sought the involvement of the most qualified researchers to help develop its research projects. In total, more than 300

scholars and academics representing more than 70 disciplines — including the social sciences, humanities, medicine, genetics, life sciences, law, ethics, philosophy, and theology — at some 21 Canadian universities and 13 hospitals, clinics, and other institutions were involved in the research program.

The Commission was committed to a research process with high standards and a protocol that included internal and external peer review for content and methodology, first at the design stage and later at the report stage. Authors were asked to respond to these reviews, and the process resulted in the achievement of a high standard of work. The protocol was completed before the publication of the studies in this series of research volumes. Researchers using human subjects were required to comply with appropriate ethical review standards.

These volumes of research studies reflect the Commission's wide mandate. We believe the findings and analysis contained in these volumes will be useful for many people, both in this country and elsewhere.

Along with the other Commissioners, I would like to take this opportunity to extend my appreciation and thanks to the researchers and external reviewers who have given tremendous amounts of time and thought to the Commission. I would also like to acknowledge the entire Commission staff for their hard work, dedication, and commitment over the life of the Commission. Finally, I would like to thank the more than 40 000 Canadians who were involved in the many facets of the Commission's work. Their contribution has been invaluable.

A handwritten signature in dark ink, reading "Patricia A. Baird". The script is cursive and fluid, with the first name "Patricia" being more prominent than the last name "Baird".

Patricia Baird, M.D., C.M., FRCPC, F.C.C.M.G.

Introduction



Crossing the threshold of a fertility clinic can be a step into a world of complex and confusing information, difficult decisions, a stressful period of treatment, and uncertainty in outcome. The studies in this volume shed light on various aspects of infertility treatment — how services are provided, to whom they are provided, and the psychosocial dimensions related to treatment. This volume is an important contribution to the literature on infertility treatment in Canada; the breadth and depth of the information it contains mean it is likely to be a primary source for those seeking information in this area for some years to come.

The three major surveys that begin the volume provide the most comprehensive picture to date of what kinds of infertility treatments are being provided in Canadian fertility clinics, what their outcomes are, what kinds of support services are available to patients, and how the patients themselves view their experiences. The second half of the volume contains studies that focus on the personal and psychosocial aspects of infertility treatment: an exploration of patient decision making, followed by two studies of the psychosocial aspects of infertility treatments based on survey data from infertile couples. The volume concludes with a literature review of existing publications on the psychosocial impact of infertility treatment on individuals and couples.

What become apparent from a careful reading of these studies are the gaps between what patients would like to have in the way of information and support and the services actually available to provide them. The patient survey and the studies of decision making and psychosocial impacts of treatment show that the services patients say they most want and find most important when they evaluate the quality of their experiences are too often in those areas in which the clinics are lacking comprehensive service. The information and counselling currently provided in most fertility clinics are frequently not sufficient to enable patients to participate

fully in exercising informed choice in decisions about their care and often give them little help in dealing with the psychosocial aspects of treatment. While most patients find the information provided about the technical aspects of treatment satisfactory, there is still a long way to go to reach the goal of providing infertility treatments in a context of clear information and support to allow patients to make informed choices.

The Studies

Thomas Stephens and Janice McLean surveyed 41 programs offering *in vitro* fertilization (IVF) and artificial insemination (AI) in 27 hospitals and clinics across Canada in 1991. They also identified a small sample of 11 physicians across Canada who were known to offer AI as part of their private practice and who offered more of this service than most physicians. The study's two primary findings, on the basis of their data, are troubling: there is a very marked variation in clinical practices and procedures across the country, and there is incomplete and unsatisfactory record keeping. The study found a wide range of clinical practices, including the use of fresh sperm for AI despite guidelines explicitly condemning this practice, as well as widely varying counselling practices; the informational material provided to patients was often not clear and readable, and consent forms varied greatly.

SPR Associates surveyed 1 395 patients in 21 fertility clinics across Canada; the findings of this survey both corroborate the findings of the clinic survey by Dr. Stephens and Ms. McLean and also clarify and add depth to the picture of current practices in Canadian fertility programs. For instance, the marked variation in practices and procedures that the clinic survey uncovered is mirrored in this survey's finding of wide variation in patients' satisfaction with the service they received from fertility programs, with the information they received, with the counselling and support services, and with the overall experience. Significantly, the information and services that were most important to patients were often not those that the clinic provided most effectively: while many clinics provided a high quality of information to their patients, it was not information about those aspects of treatment the patients most wanted covered. Information about "success rates" was particularly confusing, leading to questions about whether choice in these situations is truly informed. Many patients would have liked to have had more counselling and support, particularly after the conclusion of treatment. Overall, the survey found that how information, counselling, decision making, and informed consent procedures in clinics were handled was an important factor in predicting patient satisfaction.

The information in the SPR Associates survey also provides some demographic data on patients in Canadian fertility programs. These data are supplemented by the study by John Collins and colleagues, which collected data on the personal characteristics, diagnoses, and treatment

outcomes of some 2 200 infertile couples who were patients at infertility clinics associated with medical schools in 11 Canadian cities. Taken together, they provide a better understanding of the “demographics” of infertility treatment in Canada today.

Dr. Collins and his colleagues also provide a better understanding of how complex the process of infertility treatment is. Patients in their study are grouped by infertility diagnosis into one of nine distinct categories, and, within each category, by type of treatment and by whether it is a first or subsequent treatment. The complexity of evaluating outcomes becomes apparent, as well as the difficult nature of decision making for individuals and couples actually experiencing the treatment.

Raisa Deber and colleagues examine decision making in more depth. In doing so, they distinguish between “problem solving” and “decision making,” with the former referring to the search for the single correct solution, which requires expertise (e.g., medical diagnosis), and the latter referring to the choice of a course of action, which involves making trade-offs among various alternatives. As the three surveys that begin this volume make clear, there is opportunity for both problem solving and decision making in infertility treatment, but, as Professor Deber and her colleagues note, it is important that the former not be confused with the latter. Making an informed choice has these two different aspects, and therefore has to be a shared activity between patients and practitioners if patients’ autonomy is to be respected. New reproductive technologies are ideally suited to this, the study finds, because potential users are sufficiently healthy to comprehend the relevant information and to make decisions in light of this. Further, the decisions are elective, choices are available, and users have time to weigh the options. The complexity of decision making increases with some technologies because they have implications for additional individuals and groups, as well as for the user. These include, for example, technologies such as IVF, in which conception is separated from sexual intercourse; donor insemination, in which third-party gametes are used; and prenatal diagnosis, where the question of termination of a wanted pregnancy is at least a possibility. All this means that policy decisions regarding these categories should take into consideration societal input as well as the decisions of the individuals concerned.

Most patients in the SPR Associates survey reported a wide range of positive effects as a result of infertility treatments, including benefits to their self-esteem and their relations with their partners, but they also reported a wide range of difficulties, such as stress, physical difficulties, and financial problems. All of these have psychosocial impacts, which are the subject of the remaining three studies.

John Wright’s study of 686 francophone couples examined their adjustment to IVF, the extent to which treatment was found to be intrusive, the satisfaction with services, the reasons couples abandoned treatment, and the extent of psychosocial support services requested by couples. The

study found that a significant minority of patients were dissatisfied with one or more key elements of the services they received, a corroboration of the findings of the SPR Associates survey. Significantly, the patients in Dr. Wright's study consistently wanted more information from and dialogue with their physicians so that they would be better informed and better able to make decisions about their treatment, reinforcing Raisa Deber's identification of the importance of shared decision making. This is reflected in the finding that four of the five reasons considered most important in the decision not to continue treatment have to do with a lack of support and counselling regarding dealing with treatment: too much psychological suffering; lack of dialogue with the treating physician; lack of moral support from the medical team; and lack of information about diagnosis, treatment side-effects, and prognosis.

A separate study of how couples deal with infertility, by Antonia Abbey, Jill Halman, and Frank Andrews, further emphasizes the importance of information and support. The 275 couples who were the subject of this study were asked what advice they would give to practitioners. The most frequent response was the admonition to practitioners to be more compassionate, followed closely by suggestions for information sharing.

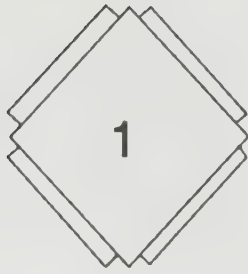
It is clear from the two preceding studies that infertility treatment places demands on the personal psychological resources of both women and men involved in this process as patients. Elizabeth Muir expands this picture with her critical review of the literature on the psychosocial implications of infertility treatment, drawn from international sources. Her work confirms these findings, especially for women, and emphasizes that both women and men undergoing infertility treatment require support that takes into account the many dimensions of these psychosocial implications.

Conclusion

Two dominant conclusions emerge from the studies in this volume. First, patients undergoing infertility treatments require information, support, and counselling to enable them to make informed choices, to participate fully in decision making about their treatment, and to deal with the inevitable psychosocial effects of the treatments. Each study contains a variation on this theme; together, they sound a clarion call.

The second conclusion is that, at present, fertility programs in Canada do not provide the information and support patients would like to have. Each survey, whether of clinics or of patients, found that the information available is too complex and does not adequately cover the areas patients find most important; that patients want more dialogue with their physicians than they are currently experiencing; and that patients want to feel a more equal partner in their treatment. It seems clear that many fertility programs need to be more patient-centred in their approach to treatment.

The light that these studies shed on the experience of infertility treatment is important for the physicians and other professionals who are involved in providing infertility treatments. The findings of these studies will enable clinics to understand how they could better serve their patients, meeting their needs not only for information and counselling, but for support in making decisions and dealing with the psychosocial impact of treatment. Taking this approach will help clinics to become truly patient-centred.



Survey of Canadian Fertility Programs

Thomas Stephens and Janice McLean



Executive Summary

Objectives

The principal objectives of this study of fertility programs in Canada were to:

- provide 1991 statistics on patients, treatments, and outcomes;
- document record-keeping practices;
- provide data regarding counselling; and
- analyze written materials that were given to patients.

Methods

Mailed questionnaires were used to collect information from:

- all Canadian programs for *in vitro* fertilization (IVF), gamete intrafallopian transfer (GIFT), and zygote intrafallopian transfer (ZIFT);
- all artificial insemination (AI) programs in hospitals and in the principal private clinics; and
- a small number of solo practitioners providing therapeutic donor insemination (TDI).

Questionnaires were received from 38 of the 41 programs and 11 of the 14 practitioners sampled (87 percent overall). The 38 fertility programs in this study were located in 27 sites; 21 of these, representing 34 programs, were visited by the research team.

The readability of English-language materials was analyzed, based on a sample of 42 items for 18 clinics.

Principal Findings

Programs and Patients

The most commonly offered assisted fertility treatment in Canada in 1991 was AI. Thirty-one of 49 programs and practitioners offered AI with husband or partner sperm (AIH) and 28 provided donor sperm. There were 227 births in 1991 as a result of TDI and 133 due to AIH.

Fifteen programs provided IVF and six offered GIFT in 1991. Thirteen of the IVF programs made use of donor sperm and eight used donor eggs or embryos. A number of programs did not provide information on the number of pregnancies resulting from donor eggs or embryos, though four pregnancies from donated eggs or embryos were reported in 1991, all in clinics outside teaching hospitals. Selective reduction and cryopreservation were each available in five programs. There were only two ZIFT programs.

Three of 11 solo practitioners reported that they used fresh sperm for TDI. Two hospitals and one solo practitioner mixed the partner and donor sperm before insemination. While many clinics receive inquiries about preimplantation diagnosis, none offered the procedure in 1991 and only one offered it at the time of the survey.

Fertility programs are highly clustered in central Canada. There are only three IVF programs outside Ontario and Quebec and one-third of the total are found in southern Ontario alone.

In 1991, there were approximately 2 900 patients in IVF programs in Canada and another 3 400 in AI programs. Ontario accounted for 70 percent of the former and 58 percent of the latter, but has 37 percent of the Canadian population.

Programs vary widely in size, particularly IVF programs, which ranged from 12 to 515 patients in 1991. One-third of the programs accounted for two-thirds of the patients.

In 1991, half the fertility programs defined "*successful treatment*" as achieving pregnancy, and birth of a live infant was a distant second choice as a way to define success. The most common method used to define pregnancy was a chemical test.

"Success" rates reported for IVF ranged from 10 to 20 percent of attempts for a live birth, and from 18 to 26 percent of attempts for a pregnancy. For TDI, the typical success rate (i.e., achieving a pregnancy) was described as 50 percent over six cycles.

One birth as a result of a surrogacy arrangement was documented in 1991.

Nineteen percent of pregnancies (243 of 1 254) resulted in a spontaneous abortion in 1991. Other outcomes, including ectopic pregnancy, therapeutic abortion, and stillbirth, were each 2 percent or less.

Among the programs for IVF and GIFT or ZIFT, the rate of spontaneous abortion in the teaching hospitals is half that of the other settings (18 vs. 34 percent), while the rates of births and continuing pregnancies are substantially higher. The reasons are not clear.

Consistent with other studies of IVF, most of the multiple pregnancies reported for 1991 were twins. Many fertility clinics in this study did not know the outcomes of the pregnancies they have assisted: one-sixth of the programs did not report any information on the outcomes of pregnancies, and one-third did not report the details of multiple births.

Patient Access

In almost half the programs, the wait for initial assessment was four weeks or less. However, the wait was more than 30 weeks in five programs, all of which were outside central Canada. Only the teaching hospitals reported delays greater than 16 weeks in 1991.

Most programs reported turning down fewer than 5 percent of the patients who sought treatment in 1991.

The most commonly reported reasons for seeking AI in 1991 were an absence of sperm or poor-quality sperm in the male partner. A vasectomy was cited in less than 10 percent of cases.

Being a lesbian or a woman without a partner was probable grounds for being refused treatment in 1991 in 19 of 49 and 20 of 49 programs, respectively. Doubtful parenting ability was a probable basis for disqualification in 10 programs.

Protocols

Hysterosalpingograms are routinely required prior to treatment by half the AI programs, while a third require an endometrial biopsy for most patients.

Half of the 16 programs for IVF or GIFT or ZIFT place no predetermined limit on the number of cycles patients may undergo.

Sperm Donors

The most common source of frozen sperm in 1991 for programs was an in-house sperm bank, with a strong majority of TDI programs not allowing patients to supply their own donors.

With the exception of one teaching hospital, all 28 programs reported that they screened sperm donors for human immunodeficiency virus (HIV) 1 and 2, syphilis, gonorrhoea, and hepatitis A and B; 25 of the 28 screened for prior sexual activity, chlamydia, and genetic history. Two clinics reported that they did not retest the donor for HIV at an interval after donation (when a test may be positive if a man was exposed just prior to donation). Human papillomavirus and trichomoniasis are screened for by half or fewer of the programs.

One-third of the AI programs (11 of 33) placed no limit on the number of inseminations per donor; seven limited inseminations to fewer than 10 per donor; nine programs permitted 15 or more pregnancies per donor.

Records

All but two of the programs and practitioners using donor sperm keep records of donor identities, and half of these plan to keep the records for at least 10 years. Three programs noted that they keep such records for less than five years, but another six did not specify the duration of record maintenance.

All IVF programs said they keep records that would allow them to classify the outcome of treatment by diagnosis. Over half also recorded the health of offspring resulting from treatment; a third tracked the mother's health for up to a year.

Half the programs do not provide information to a central IVF data base organized by physicians.

Counselling and Patient Communication

We found that counselling is usually provided to help clients cope with the stresses of treatment or to provide information. Screening is a less frequent function of counselling.

Two-thirds (32 of 49) of the programs and practitioners have a counselling specialist such as a psychologist or social worker, with 14 programs not referring outside the clinic for counselling.

Only four fertility clinics routinely collect information on patient satisfaction through the use of questionnaires.

Patient Education and Clinic Documentation

The consent forms in many programs required an estimated two years of post-secondary education to be understood, and four called for 18 or more years of education. In addition, information on the objectives of treatment and possible alternatives often is not provided to patients.

The reading levels of the patient education material ranged from grade 10 to 16, with a modal value of grade 14. These ratings raise questions about the extent to which consent can be truly informed in some programs.

Conclusions

As outlined in the Conclusions section of this report, two main areas of concern emerge from the findings of this survey of Canadian fertility clinics:

1. the accuracy and completeness of record-keeping, and the categories by which statistics are collected, leave much to be desired in many programs. This makes it difficult to judge the outcomes and quality of service being delivered. The varied and often unclear ways in which success rates are defined by different clinics make it hard for potential patients to assess programs, and mean that consent may not be fully informed. Much has been done in starting to identify standards and needs for record-keeping, and a basis developed by the profession is present to be built upon, but the great variation found in our study is not in the best interest of patients; and

2. programs vary a great deal in their actual practices, procedures, and protocols for providing fertility treatment in 1991. Standards and guidelines have been developed, such as in testing sperm donors for HIV. However, the data show that these guidelines are not followed by all practitioners. This variation in practice is true for mixing sperm in insemination, length of time records are kept, number of children per donor, etc. Assurance is needed that clinics adhere to any standards that have been developed, and there is evidence that additional standards may be needed.

Definitions of Terms Used in This Report

***In Vitro* Fertilization (IVF)**

A technique used in assisted reproduction when there is fallopian tube disease, endometriosis, sperm-cervical mucus incompatibility, male-factor infertility, or unexplained infertility. Mature oocytes (eggs) are removed from a woman's ovary, usually after administration of an ovulatory stimulant, and fertilized with sperm in the laboratory. After fertilization and incubation, the fertilized egg is placed in the woman's uterus; it may also be transferred to another woman.

Gamete Intrafallopian Transfer (GIFT)

A technique of assisted reproduction in which a woman's mature oocytes are removed by laparoscopy or by a catheter (small tube) under ultrasound guidance and then reintroduced with sperm by laparoscopy into the fallopian tubes. Because fertilization takes place *in vivo* (in the body), the procedure requires fewer laboratory facilities. It cannot, however, be used in the largest group of IVF candidates, those with fallopian tube disease. It is used for male-factor infertility, unexplained infertility, endometriosis, or where there is a problem with ovum release or incompatibility between sperm and the cervical mucus.

Zygote Intrafallopian Transfer (ZIFT)

A form of assisted reproduction in which a fertilized egg (obtained by IVF) is transferred to the fallopian tube usually by a catheter (small tube) threaded up through the uterus into the fallopian tube under ultrasound guidance. This technique has also been called pronuclear oocyte salpingo transfer (PROST), and tubal embryo stage transfer (TEST).

Artificial Insemination (AI)

The introduction of sperm into the vaginal canal, for the purpose of conception. The insemination is timed to fall just before or on the expected day of ovulation (egg release) to maximize the chance of conception.

Intravaginal insemination is technically simple and can be done without medical aid (sometimes called self-insemination). The partner's sperm, or sperm from a donor, may be used.

Therapeutic Donor Insemination (TDI)

In this report, the term therapeutic donor insemination (TDI) is used to refer to artificial insemination with donor sperm; other forms of AI are artificial insemination by husband (AIH) or intrauterine insemination (IUI). Many clinics and programs also use the term donor insemination (DI).

Introduction

Survey Objectives

The survey described in this report was carried out by Thomas Stephens and Associates in the winter of 1992 for the Royal Commission on New Reproductive Technologies. The study had five objectives:

1. provide 1991 statistics on patient case-loads, treatments provided, and treatment outcomes;
2. identify clinic objectives, definitions of key terms, non-medical criteria for admitting patients, and quality assurance procedures;
3. document the clinics' record-keeping practices, patient data bases, and statistics;
4. describe provisions for counselling and communicating with patients, and social and physical factors related to staff-patient communication; and
5. document the information provided to patients to assist them to make informed choices regarding treatment for their infertility.

Organization of This Report

The results of this study are presented in seven sections, which correspond roughly to the objectives set out above:

1. programs and patients (treatments available, patient case-loads, definitions of key terms);
2. patient access (medical and non-medical criteria, waiting lists, presenting reasons, referral practices);
3. treatment protocols (selected features of protocols and outcomes);
4. sperm donors (sources, selection, matching to recipients, payment, telling offspring);

5. records (donor sperm records, patient histories, participation in the IVF registry);
6. counselling (availability, sources, purposes and criteria, timing, clinic atmosphere); and
7. patient education and clinic documentation (content and readability of consent forms, literature on medications and procedures).

The final section of this report highlights the key findings and conclusions. As well, it identifies outstanding issues worthy of further study.

A brief description of methods (sample, data collection, response, coding) precedes the results and provides a context for them. Survey materials (blank questionnaires and interview guide) are in appendices to this report, as are details on the readability of consent forms and patient education materials. Patient education materials and completed questionnaires were assembled into separate binders.

Methods

This section describes the sample, data collection, coding, and analyses that were used to obtain the results described in later sections.

Sample

This study was designed to focus on clinics providing fertility treatments in Canada. A selected sample of solo practitioners was included to broaden understanding of the topic; this inclusion was not intended to provide a representative sample of all physicians in private practice.

Coverage was planned as follows:

- all Canadian programs of IVF, gamete intrafallopian transfer (GIFT), and zygote intrafallopian transfer (ZIFT), whether in teaching or non-teaching hospitals or in private clinics;
- all artificial insemination (AI) programs in teaching or non-teaching hospitals in Canada;
- the principal private clinics providing AI; and
- a small number of solo practitioners using frozen sperm for therapeutic donor insemination (TDI).¹

At the outset of the study, there was no definitive list of fertility programs available in Canada, and it was not possible to specify the exact numbers in each of the above groups. (Indeed, the study identified two programs in Quebec in addition to those already known, and classified as inactive or ineligible six fertility programs originally thought to qualify for this study.)

As a result of the survey, it is now possible to classify the study universe for Canadian fertility programs in hospitals and private clinics (but excluding solo practitioners) as in Table A.

Because of the small number of non-teaching hospitals and private clinics in this study, the programs in these settings have been grouped together in the presentation of results in this report. When appropriate, data from solo practitioners have been added to this group of non-teaching hospitals and private clinics.

Table A. Fertility Programs in Canada, 1991				
	Total (n)	Teaching hospitals (n)	Other hospitals (n)	Private clinics (n)
IVF / GIFT / ZIFT	17	11	2	4
Artificial insemination (AIH, IUI, TDI)	24	19	2	3

Note: Solo practitioners not included in this table.

It should be noted that the term *private* simply refers in this report to a clinic outside a publicly funded hospital.² Since some private clinicians have university appointments and bill provincial medical plans for certain procedures, while some hospital-based practitioners bill individual patients, the distinction between public and private is not altogether clear.

In most of the teaching hospitals both IVF and AI were offered, and these usually at the same site. In many important respects, however, programs tend to be distinct (e.g., different staffs, records, admission criteria, financial arrangements). Therefore, in this report, IVF and AI are considered as separate programs.

The term *program* is used in this report to describe types of fertility therapy, and the term *clinic* to describe a physical site. This terminology is also used for the private clinics and non-teaching hospitals even though their IVF and AI programs are relatively integrated compared to the teaching hospitals.

By applying this terminology to clinics and restricting ourselves to the more invasive technologies, we can summarize the clinic universe for this study (excluding solo practitioners) as consisting of 41 fertility programs in 27 sites across Canada (Table B).

These numbers do not include the many solo practitioners in Canada offering fertility therapy through medication or donor insemination. Again, the small number of solo practitioners in this study are not presented as a representative sample of such physicians.

Throughout this report, the terms *clients* and *patients* are used interchangeably. AI is used in a generic sense to refer both to AIH and to TDI. IUI is listed separately in the tables of results; this method is usually associated with insemination with husband's sperm but is also occasionally used with donor sperm.

Table B. Classification of Canadian Fertility Programs According to Activity and Setting in 1991

	Total	IVF, GIFT, ZIFT		AIH, TDI, IUI	
	All settings	Teaching hospitals	Other hospitals & clinics	Teaching hospitals	Other hospitals & clinics
All programs (27 locations)	41	11	6	19	5
Grace Hospital, Halifax	2	●		●	
Centre hosp. univ. Laval, Quebec	2	●		●	
Hôpital St-Sacrement, Quebec	1			●	
St-François d'Assise, Quebec	1			●	
Hôpital de Chicoutimi	2	●		●	
Centre hosp. univ. Sherbrooke	1			●	
Hôpital St-Luc, Montreal	2	●		●	
Montreal General Hospital	1	●			
Royal Victoria Hospital, Montreal	1			●	
Hôpital Sacré-Coeur, Montreal	1			●	
Inst. Méd. Reproduction de Montréal	2		●		●
Ottawa Civic Hospital	2	●		●	

Table B. (cont'd)

	Total	IVF, GIFT, ZIFT		AIH, TDI, IUI	
	All settings	Teaching hospitals	Other hospitals & clinics	Teaching hospitals	Other hospitals & clinics
Ottawa General Hospital	1			●	
Toronto Hospital, General Division	2	●		●	
St. Michael's Hospital, Toronto	1			●	
Toronto Fertility Sterility Institute	2		●		●
C.A.R.E. Centre, Mississauga	2		●		●
LIFE, Toronto East General Hosp.	2		●		●
IVF Canada, Scarborough	1		●		
Markham-Stouffville Hospital	2		●		●
Chedoke-McMaster Hosp., Hamilton	2	●		●	
University Hospital, London	2	●		●	
Health Sciences Centre, Winnipeg	1			●	
Royal University Hosp., Saskatoon	1			●	
Foothills Hospital, Calgary	2	●		●	
Health Sciences Centre, Edmonton	1			●	
University Hospital, Vancouver	1	●			

Data Collection

Several kinds of information were required to meet the objectives of this study; they were obtained from two principal sources:

- clinic staff, by means of questionnaire and interview (see Appendix 2); and
- clinic documentation, such as consent forms, patient literature, and some staff manuals.

Two questionnaires and a structured interview were used to collect data from clinic staff on a wide variety of topics relevant to survey objectives (1 through 4). In all cases, 1991 was clearly identified as the reporting period.

The Questionnaires

Separate questionnaires were developed for IVF programs (as well as GIFT and ZIFT) and AI programs. This provided the means to ask questions specific to these different reproductive technologies. Nevertheless, the questionnaires had many sections in common (e.g., on counselling).

The questionnaires were developed through consultation with the Commission members and staff in order to determine information needs, and through discussion with clinical and other experts representing a range of perspectives including medicine, psychology, public health, nursing, and sociology. Draft questionnaires were reviewed by two experienced physicians, but were not formally pretested due to time constraints.

Both open-ended and closed-ended questions were used. While the former are more onerous for both the respondent and the data analyst, closed categories are sometimes not desirable because they foreclose certain responses and may bias others. For example, it was deemed more informative to ask an open-ended question about clinic objectives than to present a list of options from which the most socially acceptable might be chosen. The coding of such open-ended questions is described below; the questions are identified in the Results section.

Questionnaires were delivered by courier in mid-February with a prepaid courier envelope for returning the questionnaire; a fax number was provided as an alternative means of delivery. Four covering letters were sent with the questionnaire(s); these were signed by the Commission chair and the presidents of the Society of Obstetricians and Gynaecologists of Canada (SOGC) and the Canadian Fertility and Andrology Society (CFAS) (see Appendix 2). The letter from the Commission urged return of the questionnaire within two weeks. Follow-up was conducted four to six weeks later.

In the case of hospitals, the questionnaires were sent to the hospital president or vice-president of medical affairs. These persons were asked to forward each questionnaire to the appropriate clinic director. The hope was that this would not only place the questionnaires in the right hands, but

would also lend some extra authority to the request for completion. As it turned out, this routing was the cause of innumerable delays, particularly since some questionnaires had to be routed back through the hospital bureaucracy after completion. This was not a problem with the four private clinics, where questionnaires were sent to the medical directors, and with the 14 solo practitioners, to whom the questionnaires were sent directly.

Clinic questionnaires were completed in most cases by the medical director or nurse coordinator of the clinic. Occasionally the counselling section was completed by the staff psychologist or social worker. The solo practitioners completed their own questionnaires.

The telephone was used to follow up on missing clinic questionnaires and statistical reports and to clarify certain responses. The clinic visit (see below) also provided an opportunity to clarify questionnaire responses and served to encourage questionnaire completion in preparation for the visit. Solo practitioners who did not return their questionnaires by late March were sent a reminder letter by the Commission chair, but there was no telephone contact with this group, nor was there any visit.

Clinic Visits and Interviews

Of the 38 fertility programs based in hospitals or clinics that participated in this study, 21 sites representing 34 programs were visited by the research team. Most visits were made by two of the researchers;³ Commission staff were present for nine visits. For those clinics that were not visited (Sherbrooke, Sacré-Coeur, Ottawa General Hospital, St. Michael's, Markham-Stouffville, Edmonton), some of the information normally obtained during the visits was collected by telephone.

An interview guide was used to structure the discussions during the clinic visits and to record answers and observations (see Appendix 2). When two researchers made a visit together, each maintained notes independently and these were consolidated after the interview.

The visits gave the researchers a chance to observe clinic facilities and ambience, clarify ambiguities in the questionnaires, and ask additional questions. Since the visits were mainly scheduled during March, most of the clinics had returned their questionnaires before the visit.

Clinic Documentation

Consent forms, patient education brochures, and other clinic documentation were collected primarily by mail in response to a written request from the Commission chair in July 1991. These materials were supplemented with others collected by Dr. Françoise Baylis in the spring of 1991.⁴ During the clinic visits, missing and new materials (late 1991) were requested.

Data Coding

Questionnaires

While much of the information collected through the questionnaires and interviews was in precoded categories, a significant number of write-in responses had to be coded into categories that were developed after the information was received. Such items included descriptions of objectives and definitions of key terms.

Categories were developed after examining all possible answers to a question. A single person then used these categories to code all answers, usually with only a few answers falling into the "other" category. Ambiguous answers were coded after discussion with the project director.

A similar process was used to categorize the print clinic documentation. This material was divided into three groups: consent forms, drug information, and descriptions of procedures. Staff training material and video tapes were not analyzed.

Because of the highly technical nature of much of this material, and the large inter-clinic variation in detail and subject matter, the coding was organized so as to require a minimum of expert judgment on any given topic. The content of the patient material was therefore coded by requiring a simple yes or no answer to the following questions:

- Purpose of procedure described?
- Preparation instructions described?
- Minor physical risks to patient mentioned (e.g., discomfort)?
- Major physical risks to patient mentioned (e.g., possible surgery, long-term complications)?
- Psychosocial aspects of treatment mentioned (e.g., mood swings, strain on relationship)?
- Personnel doing procedure identified?
- Aftercare instructions provided?
- Recovery time described?
- Costs described, including indirect costs such as time off work?
- Options to procedure described?
- Risk of multiple pregnancy mentioned?
- Fetal risks mentioned?

With this approach, coding reliability could reasonably be expected to be much higher than if judgments within each category were called for regarding level of detail, or adequacy or accuracy of information. However, when all of these categories are considered together, a clear picture emerges of both the detail provided and the overall adequacy of the content of the patient materials.

A similar approach was used for coding the drug information provided to clinic patients, but only a subset of these questions was used. For the consent forms, the focus was on enumerating the variety of procedures for which consent was sought, and whether or not they included full descriptions of procedures or made reference to other patient materials.

The same individual coded all the consent forms, while two coders covered the drug materials and procedures. All three worked together to ensure consistency of coding.

Readability Analysis

The readability of English-language materials was analyzed, based on a sample of 42 items for 18 clinics. These materials were selected to illustrate a range of content and styles rather than to be a representative sample from each clinic. Nonetheless, it appeared that materials from most clinics were fairly consistent in their presentation and complexity. This analysis judged reading level using the Simple Measure of Gobbledegook (SMOG) index,⁵ writing style, and visual appeal.

Readability analysis is designed to predict the level of difficulty of printed materials, that is, how easily words and sentences can be understood by the reader. The SMOG index is widely used to analyze health education materials, most notably on cancer. One of the simplest and fastest tests to use without sacrificing accuracy of prediction,⁶ the SMOG index requires a count of the number of polysyllabic words in a sample of 30 sentences. The number yielded by the SMOG grading formula is interpreted as the grade level of education necessary to ensure complete comprehension of the material. The SMOG index has a standard error of 1.5 grades.

A Resource Evaluation Checklist was used to assess other factors influencing the ease of comprehension of patient education materials.⁷ The checklist is a compilation of factors shown by past experience to influence the readability of printed materials, including content, writing style, organization, visual appeal, and illustrations. (See Appendix 3 for a sample analysis of CFAS materials using the checklist.)

Response

Table B identifies the hospitals and private clinics in this study, ordered from east to west, and indicates the programs provided and the setting (teaching hospital vs. others).

In addition to the 23 hospitals and four private clinics in Table B, information from or about another six was sufficient to classify them as inactive or otherwise ineligible as they did not provide AI or more advanced fertility treatment in 1991:

- Hôpital Notre-Dame, Montreal;
- Hôpital Maisonneuve-Rosemont, Montreal;
- Kingston General Hospital;

- Women's College Hospital, Toronto;
- St. Paul's Hospital, Vancouver; and
- Grace Maternity Hospital, Vancouver.

Questionnaires were received from 49 of the 55 programs and solo practitioners sampled (87 percent). Table C shows the response by program and setting.

Overall, response was excellent, as was cooperation with the study team in arranging the interviews and probing clinic statistics. This was probably due to several factors, including the use of three covering letters from respected individuals in professionally relevant organizations, ample time to complete the questionnaire, and the perceived importance for clinic directors of cooperating with the Commission and providing it with their perspective on clinic activities. In addition, clinic directors were provided with a description of the study's methods and purposes at the 1991 annual meeting of SOGC.

Table C. Survey Response by Program and Setting

	IVF, GIFT, ZIFT		AI		
	Teaching hospitals	Other hospitals & clinics	Teaching hospitals	Other hospitals & clinics	Solo MDs
Number eligible	11	6	19	5	14
Number responding	11	5	18	4	11
Percentage responding	100	83	95	80	79

There was also a deliberate effort by the study team to minimize the burden on clinics by coordinating data collection activities with other projects such as the patient survey.⁸ For example, the clinic survey made use of patient materials collected for an earlier project of the Commission and attempted to avoid requesting materials that had already been provided by the clinics.

Confidentiality of Responses

Because of the public domain nature of the information being collected by this study, no promises were made to clinic directors or solo practitioners that their responses would not be released to the general public. The issue of confidentiality arose only once in all the interviews and questionnaires, and then only on a minor issue.

Most of the results in this report are in aggregate form, and individual programs are not usually identified. This approach was adopted to make the results more readable and to permit comparison of programs in various settings (e.g., teaching hospitals vs. private clinics).

Results

This section presents the findings from our study. A reminder about limitations in sample coverage may be in order: the following reproductive therapies were covered: IVF, GIFT, ZIFT, AIH, IUI, and TDI. It is not known how therapies such as AI are practised outside the hospital and clinic settings surveyed. The small number of solo practitioners included in the sample are not presented as representative; they are probably more active in this field than their colleagues. Drug therapy on its own and surgery were also outside the survey's scope.

The detailed tables referred to in the section headings are in Appendix 1. A few topics have no table in the appendix, and this is noted. The totals in the tables may be derived from Table C (number responding): 11 IVF programs in teaching hospitals and five in other hospitals and private clinics, 18 AI programs in teaching hospitals and 15 in other settings of which 11 are solo practitioners' offices and four are private clinics or non-teaching hospitals. Thus, the total across all settings is 49 programs.

Programs and Patients

Types of Program

The most commonly offered treatment in these settings in Canada in 1991 was AI. Of the 49 programs and solo practitioners surveyed in this study, 31 offered AI with sperm from the husband or partner and 28 provided donor sperm (Table 1).

There were 15 programs providing IVF and six offering GIFT in 1991. Thirteen of these IVF programs used donor sperm and eight used donor eggs or embryos. Selective reduction and cryopreservation to deal with excess embryos were each available in five programs. Three of the programs with selective reduction also offered cryopreservation. There were only two programs that reportedly offered ZIFT.

Nine of the IVF programs provided the client with a choice of the number of ova to be fertilized, and 11 permitted the client to specify the number of embryos to be transferred.

AI was offered by all but two of the teaching hospitals in this study (the Montreal General and University Hospital, Vancouver); about two-thirds of them offered IVF or GIFT or ZIFT as well, usually in a separate program.

Three of 11 solo practitioners reported that they used fresh sperm for TDI. This contravenes the guideline of the CFAS that requires all semen to be quarantined for a minimum of six, and preferably 12, months to allow for any human immunodeficiency virus (HIV) seroconversion in the donor.⁹ Two hospitals (one of them teaching) and one solo practitioner used mixed partner-plus-donor sperm even though this creates confusion about the biological origins of the resulting child and is not recommended.

Methods intended to influence the sex of the conceptus were offered by one teaching hospital through dietary intervention, and by two solo practitioners. One of the latter was the Canadian licensee for a U.S. method of centrifuging sperm said to concentrate samples with either X or Y chromosomes. Virtually all clinics reported receiving requests for sex preselection. Some physicians believe it is wrong to accommodate a sex preference without a medical reason, but others referred such requests to practitioners offering services that are said to increase the chance of conceiving either a male or a female.

One non-teaching hospital reported a pregnancy from GIFT with a donated egg in 1991, and there was one surrogacy birth in another non-teaching hospital, although this was described as being under very unusual circumstances and not a regular practice.

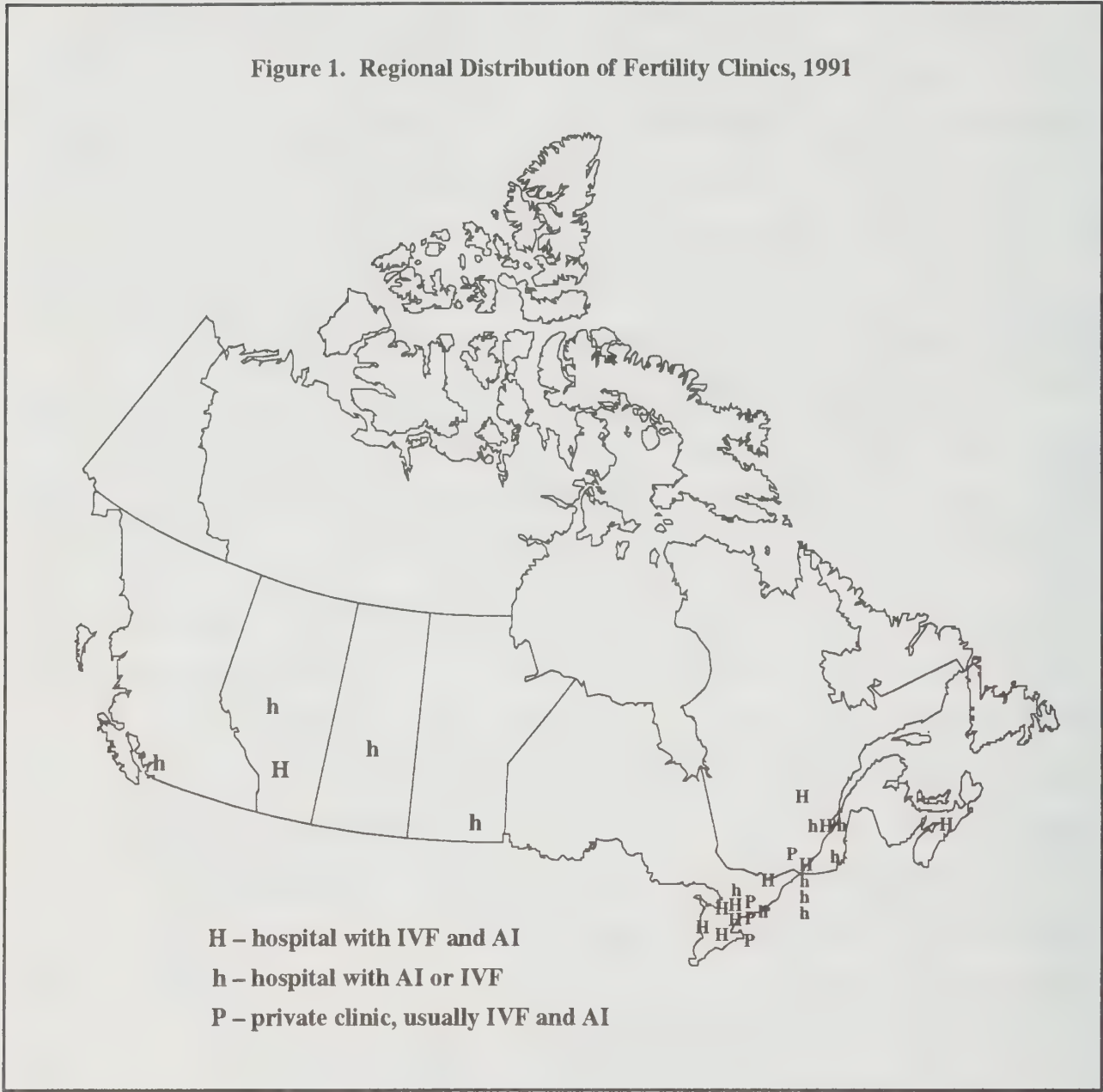
Fertility programs are highly clustered in central Canada. One-third of the total, including three of the four private clinics, are in southern Ontario alone (see Figure 1). Outside of Quebec and Ontario there are only three IVF programs — in Halifax, Calgary, and Vancouver. The Halifax and Vancouver programs do not offer donor sperm. The only IVF program in 1991 between London and Vancouver was the Regional Fertility Program in Calgary. Program expansions are planned, however, with the Winnipeg clinic having received hospital approval for IVF and Saskatoon anticipating IVF in 1993.

For a variety of reasons, the reproductive technologies offered at the clinics are not static. For example, the University of British Columbia ceased offering GIFT a few years ago because it is more invasive than IVF and the pregnancy rate was no better. Meanwhile, the Toronto Hospital anticipates adding GIFT in 1992. In 1991, the University of British Columbia introduced ZIFT by laparoscopy in a randomized study because team members were not convinced of its success; IVF Canada is offering ZIFT in 1992 and will use a special catheter for zygote transfer via the uterus so laparoscopy is not necessary.

The introduction of embryo cryopreservation reportedly results in a reduction in the number of embryos transferred in a given cycle. When extra embryos are frozen rather than transferred, the risk of multiple pregnancy decreases, and women can return, if necessary, for stimulated or natural-cycle transfers without additional egg retrieval. One physician recommended that cryopreservation be made mandatory in IVF programs.

Clinic policies regarding time limits on keeping frozen embryos range from periods of four months to 10 years (or until the woman donor would reach age 40). The four-month limit that applies in one clinic means the chances are slim that the embryos will be used for a subsequent transfer for that couple. After four months, these embryos are made available to another infertile couple. There is apparently a strong demand for such donations. In most clinics offering cryopreservation, couples have a greater chance of using the embryos in a subsequent transfer. Eventually, they have the choice to discard embryos or donate them to infertile couples or

research. One clinic requires couples to come in and dispose of the embryos they no longer want.



Selective fetal reduction continues to be available by referral from some IVF programs for multiple pregnancies, but is rarely needed and not readily done. Some programs will refer only for quadruplets, while others consider reducing triplets to twins.

Patient Case-Loads in 1991

Of the facilities with IVF programs, most provided information on the number of patients participating in 1991 (Table 2). However, three of these IVF programs provided this information only in terms of cycles. To generate an estimate of the number of patients undergoing IVF, their data have been converted by assuming an average of three IVF cycles a year per patient. Therefore, the number of patients participating in the IVF programs

surveyed is estimated at approximately 2 900 (2 494 identified directly and 377 estimated).

With respect to AI programs, most of these also provided direct patient counts. However, for three programs, it was necessary to estimate the number of patients participating in 1991. Data have been converted by assuming an average of six cycles per year for an AI patient. Therefore, the number of patients participating in AI programs surveyed is estimated at 3 400 (2 922 identified directly and 497 estimated).

Even as a description of the advanced fertility therapies, these numbers are understated: AI data were missing for six programs, and one non-teaching hospital did not report its statistics for IVF. As indicated above, a small proportion could provide only partial data, i.e., estimates from cycle information. It should also be noted that, for most clinics, "patient" is actually a couple, so there were about twice as many individuals involved in treatment. The totals reported here exclude the solo practitioners of all types as well as the clinics offering only ovulation induction through medication.

Programs varied widely in their size, and a few predominated in terms of numbers of patients. This is particularly true of IVF or GIFT or ZIFT programs, which ranged in size from 12 to 515 patients in 1991, and where one-third of the programs accounted for two-thirds of the patients. The situation was less extreme for AI, but five of the 18 teaching hospital-based programs still accounted for over half of all patients.

A disproportionate share of fertility treatment in 1991 was in Ontario: 70 percent of IVF or GIFT or ZIFT patients and 58 percent of AI patients, although this province has only 37 percent of the national population. This is likely related to the fact that Ontario has the only provincial health insurance plan that covers the procedures.

Program Objectives

Half of all fertility programs define their objective simply as providing treatment or the latest technology (Table 3). Achieving success, which itself has various definitions (see below), and helping couples achieve resolution of their infertility (whether by pregnancy, birth, or psychological closure) were cited by significant numbers of programs.

Teaching, research, and influencing the likelihood of conceiving a male or female were cited as objectives by only a few programs, although each program could list as many objectives as it wished in response to this open-ended question.

It is interesting that although IVF and GIFT or ZIFT are often seen as therapies of last resort for an infertile couple, "achieving resolution" was more likely to be cited as a goal by the AI programs. Relative to these programs, the IVF programs were likely to focus on achieving "success."

Defining Success and Pregnancy

In 1991, half the fertility programs defined successful treatment as achieving pregnancy. Live birth was a distant second choice in response to this open-ended question. For IVF and GIFT or ZIFT, non-teaching hospitals and private clinics were somewhat more likely than teaching hospitals to focus on live birth; this tendency did not extend to AI (Table 4).

The most common method used by clinics to define a pregnancy is a chemical test; 21 of 49 programs use a blood or urine test, although results were often confirmed by either a fetal heart beat or a gestational sac detected by ultrasound. Nine AI programs, but no IVF programs, defined pregnancy by progress to the second trimester or beyond (Table 5).

Programs used a variety of methods for describing chances of success to their patients. Some methods were conducive to a clear understanding; others lacked clarity. Most (10 of 16) IVF and GIFT or ZIFT programs cited the percent chance either of a pregnancy or of a birth and specified the basis for this percentage (usually per cycle). However, eight programs cited just a percentage and did not give any basis for it (Table 6). Since the question was open-ended, it may be that respondents were less precise in writing their answer to this question than in the information they actually gave to patients. However, this is open to question.

"Success" rates claimed for IVF ranged from 10 to 20 percent for a baby, and from 18 to 26 percent for a pregnancy. Such percentages were provided to patients without specifying their basis in almost half the clinics, but the most common approach was to indicate a number of cycles as the basis of the prediction of success. Some clinics reported that success rates using cryopreserved embryos were low compared to fresh embryos.

Again, chances of success with TDI, AIH, and IUI are described most often by citing percentages without specifying any basis (e.g., percentage of patients in the program). With IUI and TDI, only about one-third of programs provide a clear basis for the percentage they quote to their clients (Table 7). It is possible that some of the vagueness in describing chances of success may be in the way the questionnaire was completed and not in the way patients are advised. However, the clinic brochures and other materials were also sometimes vague. For TDI, the typical success rate was described as 50 percent over six cycles, while the highest was 90 percent (with no basis specified). For IUI, pregnancy rates claimed per cycle ranged from 7 to 20 percent.

Outcomes of Pregnancy

Hospital programs and private clinics reported 1 254 pregnancies in 1991, 609 from *in vitro*, gamete, or zygote therapies and 645 from insemination with husband (246) or donor sperm (399). There were 189 births as a result of *in vitro*, gamete, or zygote fertilization and 227 from TDI. Together these categories account for three-quarters of all such births; AIH is responsible for the balance of 133 (Table 8).

Ten private practitioners reported 511 pregnancies in 1991, of which 379 (74 percent) were a result of TDI (these data are not included in Table 8).

Incomplete statistics and a lack of standard definitions used by clinics make it impossible to calculate true "success" rates. However, since most programs reported statistics for a variety of pregnancy outcomes, it is possible to calculate the overall percent distributions and to compare groups.

Three-quarters of the pregnancies brought about by treatment in 1991 resulted in a live birth or a continuing pregnancy as of March 1992. While 19 percent of pregnancies resulted in a spontaneous abortion, other outcomes were ectopic pregnancy (2 percent), therapeutic abortion (less than 1 percent), and stillbirth (less than 1 percent).

Among IVF and GIFT or ZIFT programs, there were noteworthy differences between teaching hospitals and other settings: the rate of spontaneous abortion in the teaching hospitals was half that of the other settings (18 percent vs. 34 percent) ($\chi^2 = 17.5$, $p < 0.001$) and the rate of births and continuing pregnancies was substantially higher (74 percent vs. 61 percent) ($\chi^2 = 11.4$, $p < 0.001$). This may be due to differences in the patients accepted for treatment in the different settings, or to differences in their care.

The majority of multiple births reported in 1991 were twins. One set of triplets and one set of quadruplets were reported out of a total of 50 multiple births (Table D). Not surprisingly, IVF had the highest proportion of multiple births (23 percent). We compared this rate to the most recent data available for the general population (1990) and found 2.1 percent of all live births were multiple births. Comparison of these rates suggests that the multiple birth rate in this IVF group is 11 times as high as what we see in the population.¹⁰ In a sample of 171 births, one would not expect to have individuals who were triplets since this is normally so rare. But to find, as we did, a set of triplets and a set of quadruplets — which are even more rare in the population — is extremely uncommon.

It is noteworthy that about one-third of programs did not report these statistics. (There is no information from this study on the birth outcomes of these high-risk multiple pregnancies, and thus the costs to couples, health care systems, and society cannot be estimated.)

During the interviews, a few clinics noted that accepting patients who are less likely to become pregnant lowers the program's apparent success rate, which, in turn, may lead to the conclusion that the program is less capable. For this reason, one clinic restricted older or more medically difficult patients to 70 percent of its total with the balance made up of tubal disease patients; another accepted two-thirds with tubal disease and the balance with other causes.

One conclusion is clear from these results: many fertility clinics do not know the outcomes of all the pregnancies they have assisted. For 3 percent of all pregnancies, the outcome was unknown (Table 8); about one-

third of programs did not report whether or not a birth was a multiple one (Table D). While IVF programs know whether a pregnancy has resulted, some women return to their obstetrician and further outcome information is not obtained. AIH or TDI programs may not even know if a pregnancy resulted from treatment. One program noted that a woman's return for another insemination cycle might be the only way to know a pregnancy did not occur.

Table D. Multiple Live Births Reported for 1991

Program type and number reporting	Total number of live birth confinements	Number of these confinements that were after multiple pregnancy	% multiple birth confinements as % of live birth confinements
IVF (11/16)	171	39	23%
AI (11/18 teaching hospitals)	141	4	3%
AI (7/11 solo MD practitioners)	207	7	3%

Patient Access

Waiting Lists

Speed of access to fertility treatment varies widely from program to program in Canada. Overall, access was slower in the teaching hospitals than in other settings for all types of fertility programs in 1991 (Table 9).

The wait for initial assessment was four weeks or less in almost half (10 of 25) of the programs. However, the wait was more than 30 weeks in five programs, four of which were outside central Canada. Only these teaching hospitals reported delays greater than 16 weeks in 1991.

The interviews revealed that demand for IVF treatment dropped in some areas in 1991. This was attributed both to the recession and to the aging of the population. Time, and an end to the recession, will tell whether these explanations are correct.

Once the patient was assessed, most programs provided treatment without delay. However, further waiting was not uncommon and was most likely to occur in the teaching hospitals.

A few programs reported during the interviews that they deliberately had patients wait up to a year before proceeding with TDI. This was intended to provide time for the couples to think through the implications of donor insemination and had little to do with the availability of facilities.

Seeking Artificial Insemination

The vast majority of persons seeking AI in 1991 were either married or unmarried heterosexual couples (Table 10). Lesbian couples and women without a partner accounted for very small proportions of those seeking access to AI programs in this study.

Programs outside teaching hospitals were more likely to report women without partners seeking treatment. Otherwise, there were few differences between teaching hospitals and other settings. The apparently small numbers of single and lesbian women seeking AI may reflect an absence of demand or a well-founded suspicion on their part that they would not be accepted (see below).

By far the most commonly reported reasons for seeking AI in 1991 were an absence of sperm or poor-quality sperm (Table 11). Other reasons, such as a genetic disorder, HIV in the male, prior chemo/radiation exposure, impotence, and Rh incompatibility were quite rare.

The chances of a couple receiving TDI when they presented with male-factor infertility varied greatly from program to program. A third (11 of 33) of the programs provided donor insemination to 40 percent or fewer of such patients while seven provided it to more than 80 percent (Table 12). Male-factor infertility was more likely to be treated with donor insemination in a teaching hospital than in other settings.

Patient History

There was great variation in the duration of unexplained infertility that programs would take as evidence that IVF was appropriate. A third of the IVF and GIFT or ZIFT programs would accept patients with less than three years of unexplained infertility; a quarter would require three or more years (Table 13).

Most IVF and GIFT or ZIFT programs considered previous fertility treatment when deciding to admit a patient. The nature of this previous treatment was seldom specified on the questionnaire, suggesting few fixed criteria in this regard. One clinic reported that many of its applicants had little prior investigation (e.g., female patients who had previously been on Clomid[®] although the male partner had had no sperm analysis).

Although clinics provided details on the patient history they collected, the study did not determine how this background was used.

Professional Roles

The responsibility for setting admissions policy was evenly divided between clinic directors and the treatment team, with physician teams also playing a strong role (Table 14). It was relatively rare for the attending physician alone to set clinic policy, although he or she was most likely, along with the treatment team, to decide on individual cases.

Turning Patients Away

Most programs reported turning away fewer than five percent of the patients who sought treatment in 1991. There were slightly higher rates of refusal for AI than for IVF, but no real difference between teaching hospitals and programs in other settings (Table 15).

This result may reflect the openness of the programs, or it may be evidence of the effectiveness of clinic information programs that make their criteria for acceptance into the treatment program fairly clear, thus discouraging applications from women and couples that would likely be unsuccessful.

Even when individuals do apply and the prospect of successful treatment seems low, some programs accept them and leave the decision to proceed to the patient. This is particularly the case when patients are paying for their own treatment. In the teaching hospitals in Ontario, physicians take a more active role in deciding who will receive treatment.

The “not stated” category for this question was higher than for almost any other in this study, suggesting either that the question was a sensitive one or that records were inadequate to provide an accurate answer.

Non-Medical Criteria for Refusing Patients

Similar non-medical criteria for refusing patients were used in IVF and AI programs (Table 16). Doubtful parenting ability was a probable or possible basis for disqualification in 34 of the 49 programs. Being a lesbian or a woman without a partner was probable or possible grounds for being refused AI in 1991 in 28 of 49 and 30 of 49 programs respectively.

Certain criteria were consistently identified as *possible* grounds for denying treatment, suggesting a larger degree of judgment than for the *probable* grounds, although the basis of the judgment was not specified. These possible grounds included psychological immaturity, doubtful parenting ability, physical disability, and the woman being over age 40 (data not shown separately in Table 16).

Doubtful parenting ability seemed to include past abuse (e.g., when previous children had been removed from the home, or financial factors, such as couples on social assistance). Those clinics that did reveal such refusals stressed that these were rare.

Psychological immaturity might become evident through substance abuse. When physical disabilities were stated as reasons for possible treatment refusal, they tended to be severe (e.g., severe cerebral palsy or a couple where both were blind). However, one program was proud to have enabled a couple to achieve a pregnancy where the male had a spinal cord injury, and ejaculation, but not intercourse, was possible.

A woman's age is clearly a factor in her acceptance for fertility treatment, particularly IVF; the upper limit ranged from age 37 to age 49 at the time of acceptance into treatment. A few clinics noted that in the future, use of donor ova or embryos will raise new ethical questions about upper age limits for female patients. No restrictions on the age of the male partner were ever mentioned.

Many clinics made it clear that marital status was not a requirement in accepting couples for treatment, but it appears that a stable heterosexual relationship was. Some clinics cited hospital policy or the wishes of sperm donors in denying access to TDI to single and lesbian women. In contrast, three clinics said that a woman with a transsexual partner (born female and now male) would be considered a fertile woman with an infertile male partner; all three had accepted such couples for TDI.

Single women are sometimes accepted into treatment only after a more rigorous psychological assessment than for women with partners. One clinic noted in the interview that such policies can drive single and lesbian women to seek fresh sperm outside the medical system, using their own best judgment about the donor.

Referring to In Vitro Fertilization Programs

Most IVF programs refer applicants to other clinics if they do not accept them for treatment, although six do not refer at all (Table 17). Referral to U.S. programs is almost as common as to Canadian ones (4 vs. 6 of 16). Of the six programs making referrals to Canadian clinics, three specifically identified IVF Canada as the clinic they referred to if they did not take the patient.

Cost of Treatment

According to interviews, there are several categories of treatment in which costs limit patient access. Since patients outside Ontario must pay for IVF and GIFT or ZIFT, some choose other treatments such as tubal surgery simply because they are paid for by health insurance. The costs of certain drugs might also limit treatment; the high price of Pergonal[®] is the best known example. One clinic noted that the choice of Lupron[®] could depend on whether the couple had private drug insurance to allow them to use it if the physician thought it was the best choice. The costs of travel may also influence choice of treatment (e.g., tubal surgery could be chosen rather than IVF so that the man would not need to travel).

To increase access to AI with donor sperm for rural couples, the Winnipeg program teaches the couple how to prepare the sperm sample as well as how to do the insemination and apply the cervical cap. It is suggested they use temperature charts and an ovulation kit; sperm samples are shipped to them in dry ice. After an initial learning period, the pregnancy rate is the same as insemination at the clinic. The patient pays the extra costs but there is a net saving by avoiding the travel.

Protocols

Procedures Required Before Artificial Insemination

Hysterosalpingograms were routinely required prior to treatment by over half the AI programs; a third required an endometrial biopsy and one clinic required a laparoscopy. There are no differences between teaching hospitals and other settings with respect to these requirements (Table 18).

Whether or not these invasive and potentially risky procedures are appropriate at the outset of treatment depends on the patient's history and prior treatment, which were not determined in this study.

A few clinics continued to require a post-coital test (not shown in table), although it is thought to have limited value. One program used this test to confirm that sexual intercourse is occurring without dysfunction. Another program used this test to involve the husband in the investigation and treatment of infertility.

Maximum Cycles

Eight of the 16 IVF programs placed no predetermined limit on the number of cycles that patients may undergo. Seven of the 16 programs limited patient cycles to less than five (Table 19). There did not appear to be differences between teaching hospitals and other settings.

Interpretation of this wide discrepancy in approach is complicated by differing definitions of a cycle. Initiation was the most common definition of an IVF cycle (6 of 16 programs), while five treated embryo transfer as the criterion for a cycle. Gamete programs tended toward gamete transfer as the definition of a cycle (Table 20). Private clinics and non-teaching hospitals were similar to teaching hospitals in their usage of terminology.

AIH programs were also widely divergent in the limits placed on cycles. About equal numbers of these programs limited the maximum number of cycles to six (10 of 31 programs) or more than 10 (9 of 31). TDI cycles were most likely to exceed 10 (13 of 30 programs, Table 19). There were no apparent differences between teaching hospitals and other programs with regard to the maximum number of cycles.

In Vitro Fertilization Cycles

Three-quarters of programs (12 of 16) required patients to wait two to three months between cycles (Table 21). Programs outside teaching hospitals were more inclined toward shorter waiting periods between cycles. At least two IVF programs and one gamete transfer program ran a fixed number of patient groups each year.

Timing Artificial Insemination

Urinary detection of luteinizing hormone (LH) surge was the most common method (29 of 33 AI programs) for timing ovulation and thus insemination (Table 22). Ultrasound was also in wide use; other methods were employed relatively infrequently. Temperature charting was relatively more common in teaching hospitals; otherwise, there was little difference between teaching hospitals and other programs in their methods to time AI.

Inseminations Per Artificial Insemination Cycle

There was some preference among clinics for two inseminations of unwashed sperm per cycle, particularly from a partner but also from a donor (Table 23). With IUI and washed sperm, however, a single insemination per cycle was almost as likely as two. Teaching hospitals and other programs differed in that the former were much more likely to use two IUIs per cycle than were the latter.

Interviews in Quebec revealed a preference in that province for fewer inseminations per cycle. One physician noted that two or three inseminations per cycle produced no better results than a single insemination, and depleted the sperm bank needlessly.

Preimplantation Diagnosis

Many clinics received inquiries about preimplantation diagnosis, but only one offered the procedure, and that is in the context of a research protocol (Table 24). Only two planned to offer it within the next five years; four were uncertain, and three definitely expected not to offer it. Interviews revealed that some clinics were waiting for guidelines from the Commission before developing their plans.

Drugs

Although this study did not ask for details of medications, some views were volunteered during the interviews.

Several programs treated unexplained fertility with Clomid[®] (3 cycles in one clinic, 6 cycles in another), then tried Pergonal[®] before moving on to IVF or IUI.

IUI or AI was very often accompanied by superovulation drugs, with some programs having one cycle of treatment followed by one rest cycle. To involve the husband as much as possible, one clinic taught husbands to give the Pergonal[®] injection. One clinic moved on to diagnostic IVF after three cycles of AIH in order to confirm fertilization. There was disagreement on the usefulness of AIH.

Some IVF programs used oral contraceptives or Lupron[®] to shut down the woman's hormonal system, while others did not control cycles and the naturally occurring menstrual period was allowed to trigger a treatment cycle. Lupron[®] was also used because it was felt to stimulate more eggs and thus higher fertilization and pregnancy rates.

The use of superovulation drugs for TDI was never mentioned as routine.

Sperm Donors

Sources

The most common source of frozen sperm (11 of 33 donor programs) in 1991 was an in-house sperm bank. Repromed of Toronto and the University of Calgary were the most frequently cited sources of purchased sperm (Table 25).

Programs operating sperm banks and the two solo practitioners regularly using fresh sperm for TDI obtained it from a variety of sources, including students, hospital staff, and other doctors. One clinic also recruited policemen and firefighters.

As shown in Table 26, a strong majority of TDI programs did not allow patients to supply their own donors. This restriction was particularly true of teaching hospitals. Programs that did permit designated donors apparently did not receive many patient requests for this practice. It may

be that patients wishing such an arrangement can find it outside the formal programs.

Some sperm banks on request would set aside a sperm sample for a couple in order that they might later have a full sibling for a first child achieved through donor insemination.

Some regional differences were noted in the sources of sperm. Quebec clinics serving the francophone population made a point of obtaining sperm within Quebec, while some programs in English Canada imported sperm from a bank in the southern United States.

Paying for Sperm

Most donors were paid less than \$75 for a sperm donation. The sperm sample donated is usually split into several containers (straws), each of which is used for insemination. The cost to the recipient was typically \$125 or more (11 of 33 programs) for sperm for an insemination. In several clinics, couples paid in advance for a six-month supply of sperm and were not reimbursed if a pregnancy occurred early (Table 27).

Since there may be several inseminations from one donation, the potential profit here is considerable, even after the costs of screening, freezing, and shipping are considered.

Screening of Sperm Donors

Donors may be screened for a wide range of conditions and characteristics. With the important exception of one teaching hospital, all of the 28 programs answering this question reported that they screened for HIV 1 and 2, syphilis, gonorrhoea, and hepatitis A and B; 25 of 28 screened for prior sexual activity, chlamydia, and genetic history (Table 28). However, it is noteworthy that two clinics outside teaching hospitals reported that they did not retest the donor for HIV to see if he had become positive in the interval since donation (and thus the sperm could be infected); the largest number of programs retested every three months (Table 29).

In contrast, other conditions such as human papillomavirus and trichomoniasis were screened relatively infrequently — by half or fewer of programs.

A majority of clinics acquired their sperm only from sperm banks, and they reported the screening that they understand the banks to carry out. While the study did not seek to validate the accuracy of such reports, at least one program reported screening (hepatitis B) that the researchers knew was not in fact performed by the sperm bank supplying that program. Screening may thus be less thorough than Table 28 suggests.

Matching Donors and Recipients

The final selection of a therapeutic insemination donor was usually made by clinic staff; in only about one-third (12 of 33) of programs was the final choice of donor made by the client/couple (Table 30). Clients were much more likely to have a say in donor insemination programs outside teaching hospitals.

The husband characteristics that TDI programs were most willing to match in 1991 involved physical appearance: race, eye colour, height, weight, complexion, body type, and ethnicity. Social characteristics such as income, special abilities, intelligence, and religion seldom formed a basis for matching the donor and the recipient's partner. Programs outside teaching hospitals were more willing than those inside to match on education (Table 31).

Sometimes special considerations entered into the choice of a donor. One clinic serving a region with a high incidence of genetic disease reported couples with a severely disabled child applying for insemination with sperm from donors from outside that region.

Who Does the Insemination

AI requires entering the vagina, perhaps several times per month. A few programs had a nurse perform this task; care from a female professional may have made it less difficult for the woman patient. Other programs would not permit a nurse to carry out this function, however. In some provinces, insemination is not a delegated medical act.

Using Donor Sperm for In Vitro Fertilization

Most IVF programs used donor sperm to treat couples with male-factor infertility. However, one Salvation Army Hospital limited the use of donor sperm to TDI and would not use it for IVF. One IVF program provided the option of fertilizing half the eggs with donor sperm and half with husband sperm, if the fertilizing capacity at the time of retrieval did not appear good. Some couples have then chosen to have both types of embryo transferred despite the subsequent ambiguity about the identity of the biological father.

Inseminations and Pregnancies Per Donor

As we found with many other aspects of treatment protocols, there was a wide variety of approaches to the number of inseminations and pregnancies allowed from a given donor (Table 32).

The largest number of AI programs (11 of 33) placed no limit on the number of inseminations per donor. Seven programs limited inseminations to fewer than 10 per donor. With respect to the number of pregnancies, 13 of 33 programs limited these to fewer than 10 per donor, but an equal number (13) permitted more than 10. Limiting the number of pregnancies is impossible unless good records are kept on all pregnancies. Such records are often missing, and six of 49 programs did not record births resulting from donated sperm (see below).

Unlimited pregnancies per donor may present dangers depending to some extent on the size of the community in which the program sits; consanguineous marriage and reproduction is more likely in smaller communities. Guidelines for TDI generally recommend no more than 10 pregnancies per donor. The actual number of programs permitting more than 10 may be higher than indicated in Table 32, since there is a large number of "not stated" responses.

Telling Donor Gamete Children

There was a very strong sentiment that parents should be the ones to decide whether to tell their children if one of the biological parents is not the same as the social parent (38 of 49 programs; Table 33). This was equally true of teaching hospitals and other settings, although the teaching hospitals were more likely to provide counselling before the couple's decision.

Interviews revealed that, in practice, most parents choose not to tell their offspring about the role of donor gametes in their origins, and many clinics and sperm banks have encouraged such secrecy. This is especially the case in smaller communities.

The material from an Ontario clinic says, "Doctors advise their patients who have become pregnant following TDI to keep the nature of their conception confidential," and the consent form says, "We agree never to disclose to anyone that we have been involved in the TDI program." A Western clinic states, "You do not have to tell your doctor that the baby was conceived by artificial insemination." A U.S.-based sperm bank tells couples to think of the use of donor sperm simply as mechanical assistance.

A small minority of clinics are now choosing to talk about the existence of a biological father different from the social father. One Montreal program specifically encourages the couple to have no secrets from the child about her or his origins, and to realize and accept that their family will be slightly different from other families.

Records

On the Use of Donor Sperm

In this study, there were approximately 778 pregnancies reported (p. 21) as resulting from TDI provided by the clinics and practitioners in this study. All 40 programs providing data for this question claimed to keep records of the number of pregnancies for each donor; four of these did not record the number of children born. Only 24 recorded the number of women inseminated by each donor. It is therefore impossible to estimate the success rate of these programs (see Table 34).

The family genetic history (41 of 42 applicable) and laboratory and examination results (36 of 42) of donors were also recorded by a large number of programs. However, it is relevant that 5 percent and 14 percent of programs, respectively, did not record these important pieces of information.

In addition, these frequencies include records attributed to sperm banks. As with the data on donor screening (Table 28), the record-keeping practices of the sperm banks might not always match the expectations of their clinic customers.

On the Identity of Sperm Donors

All but two of the programs and practitioners using donor sperm kept records of donor identities, and half of these planned to keep the records for at least 10 years. Three programs stated that they kept such records for less than five years, but another six did not specify the duration of record maintenance (Table 35). Two kept no records.

Half of the AI programs would release *non-identifying* information about donors to recipients and their partners. Fewer would release such records to other parties, such as researchers, health departments, or the legal system (Table 36).

No program would release records that gave the identity of the donor to recipients, a spouse, or offspring. Four programs (of 33) said that they might be willing to release such records in response to judicial requests.

Providing Information to Sperm Donors

About a third of the TDI programs were willing to tell sperm donors about the number of pregnancies, number of children, and health of children resulting from their donation (Table 37). None was willing to identify the recipient family. Five (of 33) were willing to provide non-identifying information about the recipient family.

Patient Histories for In Vitro Fertilization and Intrafallopian Transfer

Almost all programs for IVF and GIFT or ZIFT (13 or 14 of 15 reporting) collected information about prior substance abuse by both members of a couple presenting for treatment, as well as other (medical) risks and the contraceptive history of the woman (Table 38). Occupational histories of both partners and the woman's exposure to sexually transmitted diseases are also common items of information (11 or 12 of 15 reporting).

Patient Outcomes for In Vitro Fertilization and Intrafallopian Transfer

Of the 13 IVF or intrafallopian transfer programs that provided data on this issue, all said they kept records that would allow them to classify the outcome of treatment by diagnosis. Over half (9 of 13) recorded the health of offspring resulting from treatment, but fewer than a third (4 of 13) tracked the mother's health for as much as a year (Table 39); these records were more likely to be of a summary rather than a detailed nature. There were no meaningful differences in record-keeping practices between programs inside and outside teaching hospitals. Thus one-quarter of the programs queried (4/16) did not record information on the health of infants resulting from IVF.

In Vitro Fertilization Registry Participation

Two of the 16 IVF programs were providing data to the IVF Registry (organized by physicians) for 1991 (Table 40). Of the balance, three programs were waiting for funding assistance and two for improvements to the software. Four of 16 programs were providing information for 1992.

It is evident that no comprehensive statistical data base yet exists to document activities of Canadian clinics providing IVF.

Record Maintenance

The majority of fertility clinics (15 of 23 interviewed) kept the records of their own patients separate from those of the hospital in which they were located (Table 41). Only two clinics described their records as fully integrated with the hospital's. This question provoked many spontaneous comments about the importance of patient confidentiality and how it is best protected by maintaining records separately. One consequence, however, may be a lower level of computerization of records than would otherwise be the case.

Counselling

Purposes

Counselling was provided to assist clients to cope with the stresses of treatment or to provide information for them (Table 42). Screening was a less frequent function of counselling (7 of 16 IVF programs, 14 of 31 using AIH, 6 of 30 TDI programs). There was little evidence of counselling specifically directed at helping couples cope with infertility per se.

Sources

While counselling was most often provided by medical staff, (physicians [38 of 49] and nurses [31 of 49]), two-thirds (32 of 49) of programs also had a counselling specialist such as a psychologist or social worker (Table 43). Only one-third of programs reported the existence of a patient support group.

Programs that included a social worker or psychologist were somewhat more likely to address issues of guilt, grief, and potential failure of treatment. For example, the counsellor in one donor insemination program spoke of women's disappointment at not being able to have their partner's child, and of the need for the infertile male to emotionally adopt the child of donor sperm.

Referral

When clients were referred for counselling, it was usually to a specialist such as a psychologist or psychiatrist or to a support group (Table 44). About one-quarter referred to social workers. Fourteen programs did not refer for counselling; the cost of outside counselling may be a deterrent in these and other cases.

Clients were most often referred for counselling when program staff perceived difficulty coping, although patient request (self-referral) is not uncommon (Table 45).

Receiving Counselling

Most clients were counselled as a couple; it was rare for either the female or male partner to be the only one counselled (Table 46).

Counselling usually took place before treatment (Table 47), reflecting the education and screening functions. Counselling during and after treatment was also typical in about half the programs, reflecting the coping function. This pattern held regardless of setting or type of treatment.

Allophones

Clinics reported that one member of most allophone couples under treatment spoke enough English or French to be able to translate for the other. When an interpreter was required, most clinics (15 of 23) expected the patients to bring their own, although six could provide an interpreter; some of the clinics in metropolitan areas had many languages represented among staff members (Table 48). One clinic specifies that the patient should bring a female interpreter to ensure that there is no coercion of the woman patient by the husband. One Toronto clinic has developed a handout in Chinese; this was the only material we received in a language other than English or French.

Patient Satisfaction Questionnaires

Four fertility clinics routinely collected information on patient satisfaction through the use of questionnaires (Table 49). Three clinics were starting to arrange such a procedure, but most either relied upon random feedback or had no provision for learning about patient satisfaction.

Clinic Environment

About half of the fertility clinics had baby pictures on display, representing past “successes” of the program. However, these were not usually prominently displayed in the waiting room, but were more discreetly on view in the coordinator’s office or a similar staff area (Table 50). This suggests a degree of sensitivity to the patients, and implies that the pictures may be intended more to boost staff morale than to raise patient hopes. (Staff at a few clinics mentioned the strain on people who work at fertility clinics.)

Only one-third of the clinics visited had a room set aside for the males to produce their sperm sample. A facility used for another purpose (e.g., a laboratory or a doctor’s dressing room) was almost as common an arrangement. Inappropriate facilities appear to inhibit some men, who as a consequence may be unable to provide sperm when needed. Only two clinics allowed samples to be brought from home. One clinic had arrangements to bank sperm that had been collected at home during intercourse with a special condom.

Patient Choice

Patients referred to the clinics in this study had often received prior infertility information, diagnostic work, and treatment. The study was not designed to capture the bulk of fertility procedures by private practitioners (e.g., drugs, surgery, AIH, and TDI). A few clinic physicians said some women coming to them had not been appropriately treated, notably having been treated for too long with an unsuccessful approach.

When patients arrive at fertility clinics, they may have already chosen to undergo fertility treatment with new reproductive technologies. Only a few clinics provided adoption information and a few stressed that their counselling for dealing with infertility included a range of life choices.

At most clinics, the consent forms specified some choices for patients. As well, most clinics would attempt to accommodate patient requests, e.g., for religious reasons.

Patient Education and Clinic Documentation

Consent Forms

A wide variety of consent forms was used in fertility treatment in 1991. Twenty-eight distinct procedures were the subjects of these forms, including some procedures for which there was no patient literature (Table 51).

Clinic policies concerning the use of these forms varied widely, from clinics using extremely detailed forms specific to each and every procedure in a treatment program, to one IVF clinic that used a form only for egg retrieval and treated all other procedures as routine medical care for which consent is therefore implied.

The readability of these forms also varied widely, from the clear and straightforward to the legalistic and complex. The forms in many programs (6 of 16) required an estimated two years of post-secondary education to be understood, and there were four that called for 18 or more years of education, that is, at least one graduate degree (Table E). Over half of the forms scored “poor” in overall readability, being rated low on organization, writing style, and visual appeal (see Appendix 3).

Table E. Readability of Consent Forms: Distribution of Ratings

Rating	Readability categories					SMOG	
	Writing style	Organi- zation	Visual appeal	Illustra- tions	Overall quality	Grade level	Freq.
Excellent	1	0	0	0	0	12	1
Good	1	2	2	0	2	14	6
Fair	4	5	4	0	5	15	2
Poor	10	9	10	0	9	16	2
n.a.	0	0	0	16	0	17	1
Total	16	16	16	16	16	18+	4

n.a. — not applicable

Patient Education Materials

All of the print patient-education materials collected from the teaching and non-teaching hospitals and private clinics were analyzed for content; 26 items were also analyzed for readability. Videotapes were being used in three programs and were reportedly well received, especially by allophones and patients of low literacy. The tapes were not analyzed.

In general, the materials for IVF and GIFT or ZIFT programs were the most comprehensive and informative. However, in teaching hospitals, materials systematically lacked attention to certain aspects of information that might be regarded as essential for informed participation by the client in treatment (Table 52). For example, preparation and aftercare were not routinely described, nor was there information about recovery time or optional procedures. Psychosocial aspects of embryo transfers and medications were described, but this did not extend to many other procedures. The focus of this material was on risks and costs. Retrievals, transfers, and medications were the most thoroughly covered topics.

The pattern was similar for materials from AI programs in teaching hospitals (Table 53), although costs received less attention than in the IVF programs. TDI and IUI were the most intensively covered procedures. One physician speculated that pregnancies occurring outside of treatment might have resulted when couples learned about ovulation and the timing of intercourse from reading these materials.

Compared to the teaching hospitals, the patient education material from the private clinics and non-teaching hospitals was more systematic in describing purposes and preparation; costs and options were also covered fairly routinely. Most of the attention was devoted to retrievals, transfers, medications, and TDI (Table 54).

The readability of this material, as with the consent forms, varied widely (Table F). Required reading levels ranged from grade 10 to 16, with a modal value of grade 14 (i.e., two years beyond high school). Materials from 20 of the 26 programs earned an overall grade of “fair” or “poor.”

Table F. Readability of Patient Literature: Distribution of Ratings							
Readability categories						SMOG	
Rating	Writing style	Organi- zation	Visual appeal	Illustra- tions	Overall quality	Grade level	Freq.
Excellent	2	2	2	1	1	10	1
Good	3	8	3	1	5	11	1
Fair	8	9	11	0	8	12	6
Poor	13	7	10	2	12	13	6
n.a.	0	0	0	22	0	14	9
Total	26	26	26	26	26	15+	2

Only English-language materials were analyzed for readability. Some clinics in Quebec provided French-language materials to their patients. Others provided information to patients orally, while others (e.g., Montreal) distributed English-language materials.

Combined with the results for the consent forms, these ratings raise questions about the extent to which consent in some programs can be truly informed. Nevertheless, there were some examples of excellent patient material. (See Appendix 3.)

Literature on Medications

Pamphlets and booklets from pharmaceutical companies are part of patient education materials, and it was important that information given to patients regarding medications received a separate content analysis.

Whether in teaching hospitals (Table 55) or in other settings (Table 57), cost seemed to be the most consistently covered aspect of medications for IVF and GIFT or ZIFT. Minor physical risks to the woman were also described in this literature with a fair degree of consistency. The risks of a multiple pregnancy associated with Pergonal[®] were consistently mentioned in the material handed out in private fertilization and intrafallopian transfer clinics and in the AI programs in teaching hospitals (Table 56). The university-based fertilization and intrafallopian transfer programs were not as consistent in this regard.

Informed Consent

The readability and content of the consent forms and patient education materials used in many clinics raise questions about the extent to which consent to fertility treatment is truly informed.

In a separate project for the Commission, Baylis¹¹ has identified 10 features of consent forms that are conducive to fully informed consent. Four of these are:

- a full description of the nature and objectives of the procedure and alternatives;
- information about the nature and probability of the known and possible consequences of the procedure;
- a description of the qualifications and experience of the team members; and
- information on the costs of the procedure.

Our content and readability analyses of the consent forms in our study reveal some weaknesses when compared to Baylis's criteria. The objectives of procedures are not always described and options are rarely mentioned. The risks dealt with tend to focus on the physical and give little attention to the psychosocial, except for embryo transfers. Costs are well described, in general, but the qualifications of staff are almost never provided to patients.

While some of these gaps may be filled during information nights or other oral presentations, the written materials used by the clinics in 1991 leave something to be desired in both completeness and readability.

Discussion

Emerging Issues

During the course of the interviews, a number of areas were identified as under development, with clinics either anticipating changes in the near future or looking to the Commission for guidance. Several of these are discussed briefly below.

In Vitro Fertilization with Donor Ova/Embryos

Eight of the 15 IVF programs in Canada reported offering a donor egg or embryo to clients in 1991. Although asked, the clinics gave us no information about how many such transfers were performed and no details on how many pregnancies and babies resulted from these donations. (One program reported that 12 cycles using donor ova over one and a half years had not resulted in a pregnancy.) Because of the scarcity of donor eggs, few such transfers are believed to occur. As with other new reproductive technologies, however, expansion is planned; at least one clinic intends to start a donor ova program and has already received hospital permission.

In Canada, donor ova apparently come from two sources; either women in IVF or GIFT cycles donate excess ova anonymously, or a woman who needs donor ova finds her own donor — who is usually a sister or a friend. One clinic did suggest that women requesting tubal ligation be approached to donate eggs to infertile women as part of the surgery, but there was no indication this was yet being done. There was also no evidence that women are being recruited by the clinics as donors.

Known Ova Donors

Most of the eight programs seem to permit known donors, although the ethics committee of one Toronto hospital explicitly forbids the use of known ova donors. The hospital did not explain whether this is for legal, medical, or social concerns.

At least two clinics have had babies born from sister-donated eggs. We did not ask if medical or psychological screening was required for egg donors, but a Montreal clinic said it requires both donor and recipient to be assessed in order to consider the possible effects of the superovulation drugs on the donor. It cited an example where the sister who would be the ova donor was a recently recovered schizophrenic.

No one mentioned a policy on the number of times a donor, such as a sister, could be involved, nor any criteria she would need to meet, such as age or proven fertility. There was no discussion of possible coercion within a family; however, one clinic had received a request from a woman wanting IVF using her daughter's ova.

Anonymous Ova Donors

Anonymous ova donations from women in IVF are infrequent, notably because most couples choose to have all eggs exposed to sperm with any excess embryos that result being cryopreserved where this is available.

One clinic has decided not to tell an ova donor if a pregnancy results, fearing she will become preoccupied with looking at children trying to find “hers,” particularly if she does not become pregnant with IVF.

Ova Recipients

Women may request donor ova for a variety of reasons, including primary ovarian failure, premature ovarian failure, disease (e.g., cancer), carrying a genetic problem, menopause, or repeated IVF failure. Because donated eggs are rare (a Toronto clinic has 120 women on the waiting list) some programs suggest women find a donor. This also allows for matching race and physical characteristics.

It is unclear how the decision is made on who on a waiting list is selected to receive any donated ova. No policies for such decisions were mentioned; however, several clinics see the need to create policies. Considerations could include what the age limit will be for ova recipients, what characteristics will be matched, how many cycles are permitted, etc. One clinic has set a policy that a recipient may have three tries but then moves to the bottom of the waiting list.

Information regarding specific protocols for ova recipients (e.g., natural cycle, drug-controlled cycle, cycle synchronized with known donor, or fertilizing donor ova with the recipient’s husband’s sperm for embryo cryopreservation) was not part of our study.

Embryo Donation

A child resulting from transferring donated embryos to an infertile woman is not genetically related to either social parent. There is no indication as to how often this procedure was done in 1991, even though our questionnaire specifically asked this. One Toronto clinic reported four sets of donated embryos in cryopreservation. The four-month embryo cryopreservation limit for a couple’s own use at another clinic seems certain to result in embryos for donation to others. The ethical position of one Quebec clinic is that it is better to donate unused embryos than to destroy them.

Most of the emerging policy issues noted above for ova donation (e.g., age limits, recipient selection) apply equally to embryo donation.

Controlling Access

While it is reasonably clear that physicians and the clinic teams decide clinic admissions policy, the underlying criteria or values are far from clear. Some specific instances illustrate: one clinic director believes that single women should not be encouraged to parent and thus denies them TDI; an unwritten Salvation Army policy prohibits the use of donor sperm in IVF; and various procedures — not always the same ones — are forbidden in Roman Catholic hospitals.

In this study, statements made by doctors ranged from “this is a business offering a product” to concerns about “whether this relationship is a safe place for a child.” It is not clear how the cause of infertility enters into these decisions, but there were hints that women who have been sterilized may be given lower priority when they return subsequently with another partner.

One issue raised at several clinics as a current ethical concern is whether to accept couples for TDI when the indication is that the male partner is HIV-positive.

The clinic at the University of Calgary has an innovative approach to deciding on aspects of its policies. They consult a review panel established for this purpose, which has community representation. The terms of reference for this panel are in the Notes.¹²

Patient Education

The only patient materials provided to us that related specifically to ova or embryo recipients or donors were consent forms (e.g., drug protocols, risks, success rates).

Although the use of donor gametes always involves a third party, the policies and precedents concerning sperm donation did not seem to determine decisions for ova or embryo donation. For example, sperm donors are paid, but no one proposed that egg donors be paid or that a couple receiving donated ova or embryos cover part of the IVF costs of the donor couple. It is revealing of differences in attitude that, although most of the donor ova programs would accept a woman’s sister as an ova donor, no program would accept a man’s brother as a sperm donor (and clinics do receive such requests).

Artificial Insemination and In Vitro Fertilization Surrogacy

AI surrogacy occurs when a woman is inseminated with the sperm of the intended social father, with the intention that the child will be raised by the father and his partner. There was no evidence from our data that any Canadian clinic is involved in this type of surrogacy, although requests are received and some clinics make referrals to the United States. One Quebec physician said that he thinks that AI surrogacy is practised quietly in that province. This type of surrogacy does not require new reproductive technologies, so even though the facilities we studied did not report it, it may easily be carried out elsewhere.

Gestational, IVF, or “full” surrogacy (where a couple goes through IVF to create embryos that are then transferred to another woman, who carries and bears the child for them) is planned at a Toronto clinic. Consent forms are being given final legal review, and the procedure is being reviewed by the hospital and university committees. One other program outside Ontario also reported considering IVF surrogacy.

Because the woman who carries and bears the child is not genetically related to it and because the child’s social parents are the genetic parents, clinics did not seem concerned that the woman bearing the child would want to keep it. Recruiting the women to receive these embryo transfers

and carry, bear, and relinquish the baby was not discussed; it was not apparent whether the couple or the clinic would find the women.

In discussion of procedures and future plans, no clinic volunteered information regarding the procedure whereby a woman becomes pregnant from AI, and the resulting embryo is flushed from her uterus to be transferred to another woman. We did ask the question "How many embryo transfers do you do with donated eggs?," but not specifically whether the woman bearing the fetus intended to raise the child.

Questions Needing Further Study

This study has raised a number of issues that need further study. Among them are the following:

1. the relationship of outcomes to specific treatment regimens;
2. a comprehensive data base of practitioners using AI in office-based practice, and data on their use of fresh sperm;
3. the use of fertility drugs by solo practitioners outside clinics and the frequency of multiple pregnancies that result;
4. more and better data on screening of TDI donors, including the practices of sperm banks;
5. data on information for counselling of gamete donors (whether for TDI or for egg donation); and
6. the extent of use of donor eggs and of embryos for IVF/GIFT/ZIFT.

Recommendations from Interviewees

During the course of the clinic visits, a wide range of topics was discussed. Clinic directors and staff made various recommendations regarding treatment and research:

1. all fertility clinics should use the same definitions for success rates. The definitions should specify a clinic's actual rates for pregnancy and "take-home" babies, by agreed-on standard definitions;
2. all clinics should continually evaluate their procedures and monitor outcomes (e.g., this would help understand why the spontaneous abortion rate differs between teaching and other hospitals);
3. a research centre for reproduction should be established;
4. the importance of early treatment for infertility should be stressed;
5. the reasons for the cost of Pergonal® in Canada to be higher than in other countries should be established and made clear to the public;

6. consideration should be given to the kind of sperm bank system used in France, and to approaching the fathers of healthy newborns to donate sperm as a humanitarian gesture;
7. research should be done on the causes and prevention of infertility;
8. research should be done on why fertilization or implantation does not occur;
9. counselling (including coping with guilt, past pregnancy history, grief, and alternatives to new reproductive technologies) should be more widely available, with provisions to remove cost as a deterrent;
10. psychological support needs to be provided to help staff cope with the stresses they experience in providing fertility therapy; and
11. the full extent of use of fresh sperm by solo practitioners should be established.

Conclusions

There are two main areas of concern arising from the findings of this study. The first concern is the incomplete and unsatisfactory collection of data by fertility programs; thorough data and standardized record-keeping practices are needed if this area of practice is to feed knowledge back into the shaping of good medical treatment. The second area of concern is the great variation in actual practices and procedures across the country. This includes even those practices where standards have been developed (e.g., testing sperm donors for HIV).

Concerning the first theme, this study was not primarily intended as a medical audit. However, it does seem fair to conclude that changes must be made in record-keeping to enable the development of and adherence to standards of practice. This is apparent from the answers provided by some clinics about their record-keeping practices, and from the generally poor state of the statistics that all were asked to provide. It is also apparent from the actual data given to us on the practices of the programs.

There are many findings that could be cited to illustrate the point:

- because of incomplete and inadequate record-keeping by the programs, we are unable to give reliable data on the number of live births from IVF in this country. Data on the number of pregnancies, even after advanced treatments such as IVF, are not complete or accurate. Fully one-third of the programs either did not or could not provide data on multiple births;
- incomplete statistics and the lack of standard definitions make it impossible to calculate true "success" rates. Five programs

reported cycles rather than patients. Definitions of pregnancy and other key terms vary;

- programs for AI with husband's or donor sperm may not even know if a pregnancy resulted from treatment;
- while all AI programs claimed to keep records of the number of pregnancies for each donor, four do not record the number of children born, and seven did not answer this question. Only 24 record data on the inseminations of each donor. Three TDI programs maintain insemination records for less than five years; another six did not specify the duration of records kept; four kept no records on the donor at all;
- only nine of the 13 IVF programs that answered the question recorded the health of offspring resulting from treatment, and a quarter had no information on the health of the infants. Records were more likely to be of a summary rather than a detailed nature, especially for mother's and child's health; and
- almost half the clinics gave neither patients nor public any basis for success rate. They simply provided patients with a percentage.

The second theme emerging from this study is the wide difference in approach to the provision of fertility treatment in 1991 in Canada. There appears to be as much variation or more within the group of teaching hospitals as there is between the teaching hospitals and the non-teaching hospitals and private clinics. Some findings that illustrate the point include:

- same practitioners and even one teaching hospital do not test sperm donors for HIV, as guidelines recommend;
- half of IVF and GIFT or ZIFT programs place no predetermined limit on the number of cycles that patients may undergo; others limit patient cycles to fewer than five;
- one-third of IVF and intrafallopian transfer programs would accept patients with less than a year of unexplained infertility; others require three or more years;
- programs vary widely in their size. This is particularly true of IVF programs, which ranged from 12 to 515 patients in 1991. It is difficult to see how programs doing very small numbers of procedures can maintain expertise;
- some AI programs place no limit on the number of inseminations per donor; others limit inseminations to fewer than five;
- half of programs routinely require hysterosalpingograms prior to AI treatment; others do not;
- a third of programs require an endometrial biopsy routinely before AI; the rest do not;

- some regions are served by many clinics; other regions have none; and
- procedures are supported by public health insurance in some provinces, but not in others.

Some flexibility and variation in practice may be needed to take individual situations into account, but what emerges clearly from our study is a picture of large differences in practice and procedures across the country.

Further information on the reasons underlying these variations would be valuable in determining whether and to what extent patients are served by this diversity of approaches to fertility treatment.

Appendix 1. Tables

Table 1. Infertility Treatment Available in Various Settings, Canada, 1991

Questions: IVF 1, AI 1	Total	IVF, GIFT, ZIFT		AIH, IUI, TDI	
	All settings (49)	Teaching hospitals (11)	Other hospitals & private (5)	Teaching hospitals (18)	Other hospitals & private (15)
AIH/IUI — husband/ partner sperm	31	n.a.	n.a.	16	15
TDI/IUI — donor sperm	28	n.a.	n.a.	16	12
IVF — ET	15	10	5	n.a.	n.a.
IVF with donor sperm	13	8	5	n.a.	n.a.
IVF with donor egg/ embryo	8	3	5	n.a.	n.a.
Donor insemination — known donor	7	n.a.	n.a.	0	7
GIFT	6	3	3	n.a.	n.a.
Selective embryo reduction	5	3	2	n.a.	n.a.
Embryo cryopreservation	5	2	3	n.a.	n.a.

Table 1. (cont'd)

Questions: IVF 1, AI 1	Total	IVF, GIFT, ZIFT		AIH, IUI, TDI	
	All settings (49)	Teaching hospitals (11)	Other hospitals & private (5)	Teaching hospitals (18)	Other hospitals & private (15)
AID/AIH — mixed donor/husband sperm	3	n.a.	n.a.	1	2
Donor insemination — fresh sperm	3	n.a.	n.a.	0	3
Offspring sex preselection	3	0	0	1	2
ZIFT	2	1	1	n.a.	n.a.
Embryo genetic diagnosis	2	2	0	n.a.	n.a.
Intrafallopian insemination	1	n.a.	n.a.	0	1
Surrogacy — IVF or AI	1	0	1	0	0
Peritoneal insemination	0	n.a.	n.a.	0	0

AID — Artificial insemination with donor sperm
n.a. — not applicable

Table 2. Fertility Patients/Cycles in Canada, 1991, as Reported by Programs*

Questions: IVF 15, AI 31	IVF, GIFT, ZIFT		AIH, IUI, TDI	
	Patients	Cycles	Patients	Cycles
All programs	2 494	1 131	2 922	2 982
Grace Hospital, Halifax	60		156	
Centre hospitalier univ. Laval, Quebec	41		n.s.	
Hôpital St-Sacrement, Quebec	n.a.		54	
St-François d'Assise, Quebec	n.a.		77	

Table 2. (cont'd)

Questions: IVF 15, AI 31	IVF, GIFT, ZIFT		AIH, IUI, TDI	
	Patients	Cycles	Patients	Cycles
Hôpital de Chicoutimi	18		389	
Centre hospitalier univ. Sherbrooke	n.a.		80	
Hôpital St-Luc, Montreal		123	n.s.	
Montreal General Hospital	12		n.a.	
Royal Victoria Hospital, Montreal	n.a.			970
Hôpital Sacré-Coeur, Montreal	n.a.		15	
Inst. Med. Reproduction de Montréal	154		n.s.	
Ottawa Civic Hospital	321		336	
Ottawa General Hospital	n.a.		82	
Toronto Hospital, General Division	515		392	
St. Michael's Hospital, Toronto	n.a.		n.s.	
Toronto Fertility Sterility Institute	(97)**		n.s.	
C.A.R.E. Centre, Mississauga	18		261	
LIFE, Toronto East General Hosp.		284		205
IVF Canada, Scarborough	379		n.a.	
Markham-Stouffville Hospital	n.s.		406	
Chedoke-McMaster Hosp., Hamilton	346		222	
University Hospital, London		724	225	
Health Sciences Centre, Winnipeg	n.a.		163	
Royal University Hosp., Saskatoon	n.a.		64	
Foothills Hospital, Calgary	205		n.s.	
Health Sciences Centre, Edmonton	n.a.			1 807
University Hospital, Vancouver	328		n.a.	

* Data for solo practitioners not indicated here.
 ** 1991 data not available. Number of patients based on 1990 data.
 n.a. — program not provided at hospital or clinic
 n.s. — not stated. Data not available

Table 3. Fertility Program Objectives in 1991

Questions: IVF 5, AI 7	Total	IVF, GIFT, ZIFT		AIH, IUI, TDI	
	All settings (49)	Teaching hospitals (11)	Other hospitals & private (5)	Teaching hospitals (18)	Other hospitals & private (15)
Provision of required treatment	22	3	3	9	7
Achieving pregnancy or birth	20	6	2	6	6
Helping couples achieve resolution	14	2	2	7	3
Teaching	7	1	0	5	1
Research	6	1	0	3	2
Making latest technology available	3	1	1	1	0
Influencing sex of offspring	1	0	0	0	1
Not stated	4	1	0	2	1

Note: Multiple answers were permitted to this open-ended question.

Table 4. Definitions of Successful Infertility Treatment in 1991

Questions: IVF 7, AI 9	Total	IVF, GIFT, ZIFT		AIH, IUI, TDI	
	All settings (49)	Teaching hospitals (11)	Other hospitals & private (5)	Teaching hospitals (18)	Other hospitals & private (15)
Pregnancy (see Table 5)	24	7	1	8	8
Live birth	18	3	3	6	6
Correcting physical problem	3	0	0	2	1

Table 4. (cont'd)

Questions: IVF 7, AI 9	Total	IVF, GIFT, ZIFT		AIH, IUI, TDI	
	All settings (49)	Teaching hospitals (11)	Other hospitals & private (5)	Teaching hospitals (18)	Other hospitals & private (15)
Psychological closure for couple	3	1	0	2	0
Retrieval and insemination	1	1	0	n.a.	n.a.
Transfer of embryo	1	0	1	n.a.	n.a.
As defined by client	1	0	1	0	0
Other	1	0	0	0	1
Not stated	4	0	0	2	2

Note: Multiple answers were permitted to this open-ended question.

Table 5. Methods Used to Define Pregnancy in 1991

Questions: IVF 7, AI 9	Total	IVF, GIFT, ZIFT		AIH, IUI, TDI	
	All settings (49)	Teaching hospitals (11)	Other hospitals & private (5)	Teaching hospitals (18)	Other hospitals & private (15)
Beta hCG blood test	19	2	4	8	5
Gestational sac on ultrasound	11	4	0	4	3
Fetal heart on ultrasound	10	2	2	4	2
Continuation to 2d trimester or beyond	9	0	0	4	5
Urinary test of LH surge	2	1	0	1	0

Table 5. (cont'd)

Questions: IVF 7, AI 9	Total	IVF, GIFT, ZIFT		AIH, IUI, TDI	
	All settings (49)	Teaching hospitals (11)	Other hospitals & private (5)	Teaching hospitals (18)	Other hospitals & private (15)
Expelled products of conception	3	3	0	0	0
Chorionic villus sampling	1	1	0	0	0
Other	3	1	1	1	0
Not stated	9	3	0	2	4

hCG — human chorionic gonadotropin
LH — luteinizing hormone

Note: Multiple answers were permitted to this open-ended question.

Table 6. Methods Used in 1991 to Describe a Patient's Chances of Success with IVF/GIFT/ZIFT

Question: IVF 6	IVF, GIFT, ZIFT		
	All settings (16)	Teaching hospitals (11)	Other hospitals & private (5)
% chance of pregnancy — basis specified (e.g., over x cycles)	6	3	3
% chance of pregnancy — no basis specified	4	4	0
% chance of birth — basis specified	4	2	2
% chance of birth — no basis specified	4	3	1
Too few data for a precise claim	1	1	0
Other	2	2	0
Not stated	1	1	0

Note: Multiple answers were permitted to this open-ended question.

Table 7. Methods Used in 1991 to Describe a Patient's Chances of Pregnancy with AI

	AIH		IUI		TDI	
	Teaching hospitals (16)	Other hospitals & private (15)	Teaching hospitals (16)	Other hospitals & private (13)	Teaching hospitals (16)	Other hospitals & private (14)
Question: AI 8						
% chance, basis unspecified	4	2	7	4	6	6
% chance per cycle	1	4	5	3	6	5
% chance per month	1	0	1	0	1	0
Cumulative % chance, several cycles or months	0	0	0	0	2	1
Other conditional probability	0	1	1	3	0	1
Qualitative, % not specified	2	1	2	0	0	0
Other description	4	3	0	0	1	0
Not stated	3	3	2	2	0	1

Note: Multiple answers were permitted to this open-ended question.

Table 8. Pregnancies and Outcomes Resulting from Treatment in 1991

Total		IVF, GIFT, ZIFT		TDI		AIH	
	All settings	Teaching (11)	Other (5)	Teaching (16)	Other (14)	Teaching (16)	Other (15)
Questions: IVF 15, AI 31							
Total pregnancies	1 254 (100%)	440 (100%)	169 (100%)	208 (100%)	191 (100%)	103 (100%)	143 (100%)
Live births	549 (44%)	142 (32%)	47 (28%)	108 (52%)	119 (62%)	47 (46%)	86 (60%)
Pregnancy continuing	384 (31%)	185 (42%)	55 (33%)	46 (22%)	44 (23%)	28 (27%)	26 (18%)
Spontaneous abortion	243 (19%)	81 (18%)	58 (34%)	34 (16%)	26 (14%)	20 (19%)	24 (17%)
Ectopic pregnancy	30 (2%)	19 (4%)	5 (3%)	0 (0%)	1 (<1%)	2 (2%)	3 (2%)
Therapeutic abortion	6 (<1%)	1 (<1%)	2 (1%)	1 (<1%)	0 (0%)	2 (2%)	0 (0%)
Stillbirth	5 (<1%)	1 (<1%)	2 (1%)	2 (1%)	0 (0%)	0 (0%)	0 (0%)
Unknown outcome	37 (3%)	11 (3%)	0 (0%)	17 (8%)	1 (1%)	4 (4%)	4 (3%)
Not stated (# of centres)		2	1	4	1	4	1

Note: Solo practitioners are not included.

Table 9. Waiting Lists for Fertility Treatment in 1991, by Site

Question: I 13	For assessment		For IVF		For AI	
	Teaching (20)	Other (5)	Teaching (20)	Other (5)	Teaching (20)	Other (5)
No wait	4	2	4	4	5	3
1-4 weeks	3	1	0	0	2	0
5-8 weeks	4	1	2	0	0	0
9-16 weeks	3	0	2	0	2	0
17-30 weeks	0	0	1	0	1	0
> 30 weeks	5	0	1	1	2	0
Not offered	0	0	8	0	2	1
Not stated	1	1	2	0	6	1

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Table 10. Proportion of Patients Requesting AI in 1991, by Nature of Couple Relationship

Question: AI 10	AIH, IUI, TDI		
	All settings (33)	Teaching hospitals (18)	Other hospitals & private (15)
Married couples			
< 80%	8	5	3
80-89%	10	5	5
90-99%	10	5	5
100%	4	2	2
Not stated	1	1	0
Unmarried heterosexual couples			
< 5%	9	6	3
5-9%	6	2	4
10+%	17	9	8
Not stated	1	1	0

Table 10. (*cont'd*)

Question: AI 10	AIH, IUI, TDI		
	All settings (33)	Teaching hospitals (18)	Other hospitals & private (15)
Lesbian couples			
0%	19	8	11
1-4%	8	6	2
5-9%	5	3	2
10+%	0	0	0
Not stated	1	1	0
Women with no partner			
0%	11	5	6
1-4%	10	8	2
5-9%	5	3	2
10+%	6	1	5
Not stated	1	1	0

Table 11. Proportion of Patients Requesting AI in 1991, by Nature of Presenting Problem

Question: AI 11	AIH, IUI, TDI		
	All settings (33)	Teaching hospitals (18)	Other hospitals & private (15)
No sperm			
< 5%	1	1	0
5-14%	5	4	1
15-49%	11	5	6
50-74%	8	3	5
75-100%	2	1	1
Not stated	6	4	2

Table 11. (cont'd)

Question: AI 11	AIH, IUI, TDI		
	All settings (33)	Teaching hospitals (18)	Other hospitals & private (15)
Poor-quality sperm			
< 5%	0	0	0
5-14%	1	1	0
15-49%	16	6	10
50-74%	5	3	2
75-100%	5	4	1
Not stated	6	4	2
Vasectomy			
< 5%	10	5	5
5-14%	13	7	6
15-49%	2	1	1
50-75%	1	0	1
Not stated	7	5	2
Genetic disorder			
< 2%	18	11	7
2-4%	5	2	3
5-10%	4	1	3
Not stated	6	4	2
Prior chemo/radiation exposure			
< 2%	16	9	7
2-4%	6	2	4
5-10%	5	3	2
Not stated	6	4	2
Male HIV positive			
< 2%	26	13	13
2-4%	1	1	0
5-10%	0	0	0
Not stated	6	4	2

Table 11. (cont'd)

Question: AI 11	AIH, IUI, TDI		
	All settings (33)	Teaching hospitals (18)	Other hospitals & private (15)
Impotence			
< 2%	22	11	11
2-4%	4	2	2
5-10%	1	1	0
Not stated	6	4	2
Rh incompatibility			
< 2%	27	14	13
2-4%	0	0	0
5-10%	0	0	0
Not stated	6	4	2

Table 12. Proportion of Male-Factor Infertility Receiving Treatment by Donor Insemination in 1991

Question: AI 12	AIH, IUI, TDI		
	All settings (33)	Teaching hospitals (18)	Other hospitals & private (15)
0-20%	5	2	3
21-40%	6	2	4
41-60%	5	2	3
61-80%	2	0	2
81-100%	7	5	2
Not applicable	1	1	0
Not stated	7	6	1

Table 13. Duration of Unexplained Fertility as a Factor in Deciding Admission to IVF Treatment in 1991

	IVF, GIFT, ZIFT		
	All settings (16)	Teaching hospitals (11)	Other hospitals & private (5)
Question: IVF 8			
Minimum 1 year, unqualified	2	2	0
Minimum 1 year with IUI and sperm washes	2	1	1
Minimum 2-3 years	2	2	0
Minimum 3+ years	4	3	1
Time period varies/conditional	5	2	3
Not applicable	1	1	0
Not stated	0	0	0

Table 14. Roles in Deciding on Patient Admission in 1991

	All settings (24)	Teaching hospitals (20)	Other hospitals & private (4)
Questions: I 9, 10			
Establishing admissions policy			
Treatment team	6	5	1
Medical director	6	5	1
Physician team	5	4	1
Attending physician	3	3	0
Counsellor	0	0	0
Other	3	2	1
Not stated	1	1	0

Table 14. (cont'd)

Questions: 19, 10	All settings (24)	Teaching hospitals (20)	Other hospitals & private (4)
Deciding individual cases*			
Treatment team	7	5	2
Medical director	6	4	2
Attending physician	7	7	0
Physician team	3	3	0
Counsellor	1	1	0
Other	2	1	1
Not stated	1	1	0

* Multiple responses were permitted.

Table 15. Proportion of Patients Requesting Treatment in 1991 Who Were Turned Away

	Total	IVF, GIFT, ZIFT		AIH, IUI, TDI	
Questions: IVF 10, AI 13	All settings (49)	Teaching hospitals (11)	Other hospitals & private (5)	Teaching hospitals (18)	Other hospitals & private (15)
< 5%	18	6	2	6	4
5-9%	4	0	0	2	2
10-14%	3	1	0	1	1
15+%	6	0	0	2	4
Not applicable	2	1	1	0	0
Not stated	16	3	2	7	4

Table 16. Non-Medical Reasons for Refusing* Fertility Treatment in 1991

Questions: IVF 9, AI 14	Total	IVF, GIFT, ZIFT		AIH, IUI, TDI	
	All settings (49)	Teaching hospitals (11)	Other hospitals & private (5)	Teaching hospitals (18)	Other hospitals & private (15)
Doubtful parenting ability	34	8	3	13	10
Psychological immaturity	31	5	3	13	10
Women aged > 40	31	7	3	9	12
Unmarried without partner	30	7	3	9	11
Homosexual (lesbian)	28	7	2	9	10
Below average intelligence	19	2	1	7	9
Physically disabled	18	3	2	5	8
Woman aged < 18	16	4	1	7	4
Other living children	8	2	1	0	5
Low income	7	1	0	1	5
Unmarried with partner	7	0	0	1	6
Province of residence	6	1	1	1	3
Country of residence	6	1	1	1	3
Other	4	2	1	1	0
Not stated	1	1	0	0	0

* "Possible" and "probable" grounds for refusal.

Table 17. Referral of Patients in 1991 Who Were Not Accepted for IVF Treatment

Question: IVF 11	IVF, GIFT, ZIFT		
	All settings (16)	Teaching hospitals (11)	Other hospitals & private (5)
Not referred	6	4	2
To IVF Canada	3	2	1
To other private clinics (Canadian)	2	2	0
To teaching hospitals (Canadian)	1	1	0
To U.S. clinics	4	3	1
Other	4	2	2
Not stated	0	0	0

Note: Multiple answers were permitted to this open-ended question.

Table 18. Programs Requiring Various Diagnostic and Other Procedures Before AI Treatment in 1991

Question: AI 6	AIH, IUI, TDI		
	All settings (33)	Teaching hospitals (18)	Other hospitals & private (15)
Temperature charting	24	13	11
Hysterosalpingogram	18	10	8
Hormonal profile	15	4	11
Sperm-mucous test	10	5	5
Endometrial biopsy	9	4	5
Serial ultrasound	7	2	5
Ovulation induction	4	1	3
Sperm antibody evaluation	3	3	0
Laparoscopy	1	0	1

Table 19. Maximum Cycles Allowed in Fertility Treatment in 1991

Questions: IVF 4, AI 15	IVF		AIH		TDI	
	Teaching hospitals (11)	Other hospitals & private (5)	Teaching hospitals (16)	Other hospitals & private (15)	Teaching hospitals (16)	Other hospitals & private (14)
< 5 cycles*	5	2	1	1	2	1
6 cycles	1	0	5	5	2	4
> 10 cycles	0	0	4	5	8	5
Unlimited	5	3	3	1	3	2
Not stated	0	0	3	3	1	2

* Definitions of cycle vary; see Table 20.

Note: If a range was given, the upper limit was recorded.

Table 20. Definitions of IVF and GIFT Cycles in 1991

Question: IVF 7	IVF		GIFT	
	Teaching hospitals (11)	Other hospitals & private (5)	Teaching hospitals (11)	Other hospitals & private (5)
Embryo/gamete transfer	3	2	2	2
Initiation of cycle	4	2		
Retrieval and insemination	2	0		
Not stated	1	1	1	1
Not applicable	1	0	8	2

Note: Multiple answers were permitted to this open-ended question.

Table 21. Minimum Time Allowed Between IVF Cycles in 1991

Question: IVF 4	IVF, GIFT, ZIFT		
	All settings (16)	Teaching hospitals (11)	Other hospitals & private (5)
1 month	1	0	1
2 months	6	2	4
3 months	6	6	0
More than 3 months	3	3	0
Not stated	0	0	0

Table 22. Methods Used to Time AI in 1991

Question: AI 5	AIH, IUI, TDI		
	All settings (33)	Teaching hospitals (18)	Other hospitals & private (15)
Ovulation prediction test (urine)	29	14	15
Ultrasound	24	12	12
Temperature charting	14	10	4
LH surge (blood)	10	5	5
hCG injection	3	3	0
Mucous test (volume and viscosity)	3	3	1
Calendar calculation	1	1	0
Other	0	0	0
Not stated	0	0	0

Note: Multiple answers were permitted to this open-ended question.

Table 23. Usual Number of Inseminations per AI Cycle in 1991

Question: AI 4	AIH, IUI, TDI		
	All settings (33)	Teaching hospitals (18)	Other hospitals & private (15)
Donor sperm (unwashed)			
1	6	3	3
2	20	11	9
3	3	2	1
6	1	0	1
Not applicable	2	2	0
Not stated	1	0	1
Husband sperm (unwashed)			
1	7	4	3
2	12	7	5
9	1	0	1
Not applicable	5	3	2
Not stated	8	4	4
IUI (washed sperm)*			
1	13	6	7
2	16	12	4
3	1	0	1
Not applicable	0	0	0
Not stated	3	0	3

* Most washed sperm is from the husband or partner.

Note: If a range was given, the higher number was recorded.

Table 24. Preimplantation Diagnosis in Fertility Clinics in 1991

Questions: I 25, 26	All settings (24)	Teaching hospitals (20)	Other hospitals & private (4)
Received inquiries	9	8	1
Offer procedure currently	1	1	0
Plan to offer within 5 years	2	1	1
Uncertain about plans	4	4	0
Do not plan to offer	3	2	1
Not applicable	7	7	0
Not stated	6	5	1

Note: Multiple answers were permitted to this question.

Table 25. Sources of Sperm Used in TDI Programs in 1991

	All settings (33)	Teaching hospitals (18)	Other hospitals & private (15)
Questions: AI 24, 25, 21			
Frozen sperm (sperm bank)			
In-house	11	9	2
Repromed (Toronto)	6	4	2
Calgary	5	4	1
Xytex (U.S.)	2	2	0
Other Canadian	2	1	1
Other U.S.	2	0	2
Other	4	1	3
Not applicable	5	2	3
Not stated	1	0	1
Fresh sperm			
Patient's relatives / friends	2	0	2
Medical students	1	0	1
Graduate students	1	0	1
Hospital staff	1	0	1
Other doctors	1	0	1
Other	3	0	3
Not applicable	29	18	11
Not stated	0	0	0

Note: Multiple answers were allowed to the open-ended question on sources of frozen sperm as well as the closed-ended question on sources of fresh sperm.

Table 26. Proportion of TDI Recipients Who Wished to Provide Own Donor Sperm in 1991

	TDI		
	All settings (33)	Teaching hospitals (18)	Other hospitals & private (15)
Question: AI 22			
0-10%	4	0	4
11-90%	0	0	0
91-100%	1	0	1
Practice not allowed	24	16	8
Not applicable	3	2	1
Not stated	1	0	1

Table 27. Payment for Sperm Donations in 1991

Questions: AI 23, 24	TDI		
	All settings (33)	Teaching hospitals (18)	Other hospitals & private (15)
To donors			
< \$50	4	4	0
\$50-74	8	6	2
\$75-99	2	0	2
\$100+	3	0	3
Not applicable	16	8	8
Not stated	0	0	0
By recipient			
< \$50	0	0	0
\$50-74	2	2	0
\$75-99	2	1	1
\$100-124	2	0	2
\$125+	11	5	6
Not applicable	12	8	4
Not stated	4	2	2

Note: The donated sperm is usually split into several containers or “straws.” The cost to the recipient, shown here, is therefore not directly comparable to the figures for payment to the donor.

Table 28. Characteristics of Potential Sperm Donors Screened in 1991

Questions: AI 28-30	TDI		
	All settings (33)	Teaching hospitals (18)	Other hospitals & private (15)
Gonorrhoea	27	15	12
Hepatitis A and B	27	15	12
HIV 1 and 2	27	15	12
Syphilis	27	15	12
Chlamydia	25	14	11

Table 28. (cont'd)

Questions: AI 28-30	TDI		
	All settings (33)	Teaching hospitals (18)	Other hospitals & private (15)
Genetic history	25	14	11
Sexual activity	25	13	12
Sexual orientation	24	13	11
Cytomegalovirus	19	10	9
Herpes	17	8	9
Trichomoniasis	17	10	7
Ejaculate C & S	16	8	8
Chromosomal analysis	13	8	5
Human papillomavirus	12	6	6
Tuberculosis	8	3	5
Not stated	1	0	1
Not applicable	4	2	2

C & S — culture and sensitivity

Note: Includes screening attributed to sperm banks.

Table 29. Repeat Testing of Sperm Donors for HIV in 1991

Questions: AI 28-30	TDI		
	All settings (33)	Teaching hospitals (18)	Other hospitals & private (15)
< Every 3 months	3	2	1
Every 3 months	12	9	3
Every 6 months	7	3	4
No retesting	2	0	2
Not stated	4	1	3
Not applicable	5	3	2

Table 30. Final Selection of Sperm Donor in 1991

Question: AI 27	TDI		
	All settings (33)	Teaching hospitals (18)	Other hospitals & private (15)
Final selection normally by			
Client/couple	12	3	9
Nurse	7	6	1
Doctor	5	3	2
Staff, unspecified	5	4	1
Sperm bank	3	1	2
Laboratory director	2	1	1
Not applicable	3	2	1
Not stated	2	2	0

Note: Multiple responses were permitted to this open-ended question.

Table 31. Sperm Donor Characteristics That Fertility Clinics Were Willing to Match in 1991

Question: AI 26	TDI		
	All settings (33)	Teaching hospitals (18)	Other hospitals & private (15)
Height	25	15	10
Eye colour	25	15	10
Race	25	13	12
Weight	23	13	10
Complexion	22	13	9
Ethnic or national origin	22	14	8
Body type	21	10	11
Hair texture	19	8	11
Religion	12	6	6
Education	12	3	9
Hobbies or interests	8	3	5
Special abilities	7	2	5
IQ	6	1	5

Table 31. (cont'd)

	TDI		
	All settings (33)	Teaching hospitals (18)	Other hospitals & private (15)
Question: AI 26			
Age	5	1	4
Income	4	1	3
Other	10	8	2
Not applicable	4	2	2
None stated	2	1	1

Table 32. Maximum Number of Inseminations and Pregnancies Allowed Per Donor in 1991

	AIH, IUI, TDI		
	All settings (33)	Teaching hospitals (18)	Other hospitals & private (15)
Question: AI 15			
Inseminations			
< 5	3	2	1
5-9	4	3	1
10-14	3	1	2
Unlimited	11	6	5
Not applicable	3	2	1
Not stated	9	4	5
Pregnancies			
< 5	4	0	4
5-9	9	8	1
10-14	4	3	1
15-30	6	2	4
Unlimited	3	0	3
Not applicable	3	2	1
Not stated	4	3	1

Table 33. Advice to Parents About Telling Children of Their Origin Through Donor Gametes, 1991

Questions: IVF 20, AI 36	Total	IVF		TDI	
	All settings (49)	Teaching hospitals (11)	Other hospitals & private (5)	Teaching hospitals (18)	Other hospitals & private (15)
Let parents decide	26	3	5	8	10
Let parents decide after counselling	12	4	0	7	1
Tell child nothing	3	0	0	0	3
Tell child about biological father	2	1	0	1	0
Not applicable	6	3	0	2	1
Not stated	0	0	0	0	0

Table 34. Records Kept in 1991 on Use of Donated Sperm

Questions: IVF 13, AI 17	Total	IVF, GIFT, ZIFT		AIH, IUI, TDI	
	All settings (49)	Teaching hospitals (11)	Other hospitals & private (5)	Teaching hospitals (18)	Other hospitals & private (15)
Pregnancies achieved	40	8	5	15	12
Family genetic history	41	8	5	16	12
Children born	36	8	4	13	11
Exam and lab test results	36	6	5	15	10
Follow-up exam results	34	6	5	14	9
Follow-up lab results	34	6	5	14	9
# of women inseminated	24	n.a.	n.a.	14	10
Not applicable	7	4	0	2	1
Not stated	2	0	0	0	2

Note: Includes records maintained by sperm banks.

Table 35. Records Kept in 1991 on Identity of Sperm Donors

	TDI		
	All settings (33)	Teaching hospitals (18)	Other hospitals & private (15)
Question: AI 16			
Records kept by clinic			
< 5 years	3	3	0
5-9 years	5	5	0
10-19 years	6	2	4
20-29 years	1	0	1
unlimited duration	9	6	3
duration unspecified	6	1	5
No records kept	2	0	2
Not stated	1	1	0

Table 36. Willingness to Release Information on Sperm Donors in 1991

	TDI		
	All settings (33)	Teaching hospitals (18)	Other hospitals & private (15)
Question: AI 18			
Would release donor record without identification			
to recipient	16	8	8
to recipient's partner	15	8	7
to judicial requests	8	4	4
to offspring	7	3	4
to health department	5	4	1
to research scientists	5	3	2
to insurance company	1	0	1
Not applicable	3	2	1
Not stated	3	1	2

Table 36. (cont'd)

	TDI		
	All settings (33)	Teaching hospitals (18)	Other hospitals & private (15)
Question: AI 18			
Would release donor record with identification			
to recipient	0	0	0
to recipient's partner	0	0	0
to judicial requests	4	3	1
to offspring	0	0	0
to health department	1	1	0
to research scientists	1	1	0
to insurance company	1	1	0
Not applicable	3	2	1
Not stated	3	1	2

Table 37. Information That Programs Were Willing to Provide to Sperm Donors in 1991

	TDI		
	All settings (33)	Teaching hospitals (18)	Other hospitals & private (15)
Question: AI 19			
Number of pregnancies	12	8	4
Number of children	10	6	4
Health of children	10	7	3
Non-identifying information about recipient family	5	2	3
Identification of recipient family	0	0	0
Not applicable	4	3	1
Not stated	2	0	2

Table 38. Patient Histories Collected by IVF/GIFT/ZIFT Programs in 1991

	IVF, GIFT, ZIFT		
	All settings (16)	Teaching hospitals (11)	Other hospitals & private (5)
Question: IVF 14			
Prior substance use/abuse — woman	14	10	4
Prior substance use/abuse — man	13	9	4
Sexually transmitted diseases — woman	12	9	3
Occupational history — woman	11	9	2
Occupational history — man	11	9	2
Contraceptive history — woman	13	8	5
Contraceptive history — man	8	6	2
Current substance use/abuse — woman	10	8	2
Current substance use/abuse — man	9	8	1
Sexual abuse — woman	4	2	2
Other risks for infertility — woman	14	9	5
Other risks for infertility — man	14	9	5
Not stated	1	1	0

Note: At least summary-level information collected. Some clinics collected detailed information, but this was the exception.

Table 39. Patient Outcome Information Collected by IVF/GIFT/ZIFT Programs in 1991

	IVF, GIFT, ZIFT		
	All settings (16)	Teaching hospitals (11)	Other hospitals & private (5)
Question: IVF 14			
Outcome of treatment classified by diagnosis	13	9	4
summary	6	5	1
detailed	7	4	3

Table 39. (cont'd)

Question: IVF 14	IVF, GIFT, ZIFT		
	All settings (16)	Teaching hospitals (11)	Other hospitals & private (5)
Mother's health for one or more years	4	3	1
summary	3	3	0
detailed	1	0	1
Health of child (duration unspecified)	9	6	3
summary	8	5	3
detailed	1	1	0

Note: Distinctions between summary and detailed information were made by the clinics. A claim of detailed information had to be supported by a blank patient questionnaire.

Table 40. Participation in IVF Registry in 1991

Question: IVF 12	IVF, GIFT, ZIFT		
	All settings (16)	Teaching hospitals (11)	Other hospitals & private (5)
Providing data			
for 1992	4	2	2
for 1991	2	1	1
for earlier years	2	2	0
Not providing data			
awaiting improvements to software	2	2	0
awaiting funding	3	2	1
other reason	1	0	1
not applicable	2	2	0

Table 41. Maintenance of Client Records by Fertility Clinics in 1991

Question: I 16	All settings (24)	Teaching hospitals (20)	Other hospitals & private (4)
Maintained separately	15	12	3
Integrated with hospital	2	2	0
Other	3	2	1
Not stated	4	4	0

Table 42. Purposes of Counselling in Fertility Programs in 1991

	IVF		AIH		TDI	
	Teaching hospitals (11)	Other hospitals & private (5)	Teaching hospitals (16)	Other hospitals & private (15)	Teaching hospitals (16)	Other hospitals & private (14)
Questions: IVF 19, AI 35						
Assist with coping	10	5	10	3	15	6
Provide information	9	2	9	8	10	8
Screen patients	3	4	7	7	2	4
Counselling not available	1	0	2	0	0	0
Not applicable	3	0	0	0	2	1
Not stated	9	0	2	5	0	2

Note: Multiple answers were permitted to this open-ended question.

Table 43. Sources of Counselling in Fertility Programs in 1991

	Total	IVF, GIFT, ZIFT		AIH, IUI, TDI	
	All settings (49)	Teaching hospitals (11)	Other hospitals & private (5)	Teaching hospitals (18)	Other hospitals & private (15)
Questions: IVF 17, 18, AI 33, 34					
Physician	38	7	4	15	12
Psychologist or social worker	32	9	4	13	6
Nurse	31	7	4	14	6
Support group	17	3	3	6	5
Psychiatrist	9	2	1	3	3
Other	5	2	1	0	2
Not stated	0	0	0	0	0

Note: Multiple answers were permitted to this question.

Table 44. Types of Counsellors to Whom Patients Were Referred in 1991

Questions: IVF 22, AI 38	Total	IVF, GIFT, ZIFT		AIH, IUI, TDI	
	All settings (49)	Teaching hospitals (11)	Other hospitals & private (5)	Teaching hospitals (18)	Other hospitals & private (15)
Psychologist	19	3	1	12	3
Psychiatrist	17	3	3	5	6
Support group	16	2	3	6	5
Social worker	12	2	0	7	3
Nurse	8	2	0	5	1
Physician	7	2	0	4	1
Clergy	2	0	0	2	0
Other	2	1	0	0	1
No referral	14	5	2	2	5
Not stated	0	0	0	0	0

Note: Multiple answers were permitted to this closed-ended question.

Table 45. Criteria for Referring Patients to Counselling in 1991

Questions: IVF 23, AI 39	Total	IVF, GIFT, ZIFT		AIH, IUI, TDI	
	All settings (49)	Teaching hospitals (11)	Other hospitals & private (5)	Teaching hospitals (18)	Other hospitals & private (15)
Problem perceived by clinic	21	6	1	8	6
Patient request	14	3	3	5	3
Obligatory part of treatment	11	1	1	4	5
No referral	9	3	0	3	3
Other	3	0	0	2	1
Not stated	4	1	1	2	0

Note: Multiple answers were allowed to this open-ended question.

Table 46. Proportion of Fertility Patients Who Received Counselling in 1991

	Total	IVF, GIFT, ZIFT		AIH, IUI, TDI	
Questions: IVF 16, AI 32	All settings (49)	Teaching hospitals (11)	Other hospitals & private (5)	Teaching hospitals (18)	Other hospitals & private (15)
As couples					
0%	1	1	0	0	0
1-49%	6	1	1	3	1
50-99%	13	3	2	3	5
100%	24	5	1	11	7
Not stated	5	1	1	1	2
Male partner only					
0%	32	6	2	13	11
1-4%	4	1	1	2	0
5-14%	3	2	0	1	0
15-50%	2	0	0	0	2
Not stated	8	2	2	2	2
Female partner only					
0%	21	4	2	9	6
1-4%	0	0	0	0	0
5-14%	11	4	1	4	2
15-50%	6	2	0	2	2
100%	5	0	0	2	3
Not stated	6	1	2	1	2

Table 47. Timing of Counselling Sessions in Fertility Treatment in 1991

Questions: IVF 21, AI 37	Total	IVF, GIFT, ZIFT		AIH, IUI, TDI	
	All settings (49)	Teaching hospitals (11)	Other hospitals & private (5)	Teaching hospitals (18)	Other hospitals & private (15)
Before treatment	40	9	5	14	12
During treatment	33	9	3	14	7
After treatment	28	10	3	10	5
Not stated	0	0	0	0	0

Note: Multiple answers were permitted to this question.

Table 48. Provisions for Communicating with Clients Who Did Not Speak English/French in 1991

Question: I 22	All settings (24)	Teaching hospitals (20)	Other hospitals & private (4)
Clients provide own interpreter	15	13	2
Clinic staff provides most interpretation	9	7	2
Hospital services provide interpretation	6	6	0
No demand, not an issue	2	2	0
Other provision	2	2	0
Not stated	3	2	1

Notes: 1. Multiple answers were permitted to this open-ended question.
2. Question referred to French in Quebec, English elsewhere.

Table 49. Use of Client Satisfaction Questionnaires in Fertility Programs in 1991

Question: I 24	All settings (24)	Teaching hospitals (20)	Other hospitals & private (4)
None specified	9	7	2
Routinely administered	4	3	1
Starting to arrange	3	3	0
Random feedback	4	4	0
Organized by patients	1	1	0
Not stated	2	2	0

Note: Multiple answers were permitted to this open-ended question.

Table 50. Clinic Environment in 1991

Question: I 30	All settings (24)	Teaching hospitals (20)	Other hospitals & private (4)
Display of baby pictures			
In coordinator's / other office	9	7	2
None in evidence	7	5	2
In waiting area	3	3	0
Not stated	4	5	0
Room used for production of sperm sample			
Dedicated room	7	5	2
Other shared facility	6	4	2
None — done at home	2	2	0
Not stated	7	7	0

Note: Multiple answers were permitted to these open-ended questions.

Table 51. Consent Forms Used in Fertility Programs in 1991

Procedure	Total (34)	IVF/GIFT/ZIFT Teaching hospitals (11)	AIH/TDI/UI Teaching hospitals (18)	Private clinics & other hospitals* (5)
Diagnostic tests	12	6	3	3
Access records	7	1	2	4
TDI — donor	11	1	7	3
TDI — donor spouse	7	1	6	0
TDI — recipient	17	0	12	5
TDI — spouse	14	0	9	5
IUI/AIH	4	0	3	1
Stimulate ovulation	4	0	3	1
Use other drugs	1	1	0	0
Bank sperm	4	1	2	1
Dispose of sperm	2	0	2	0
Test for HIV	4	0	1	3
IVF-ET	14	9	n.a.	5
GIFT	2	2	n.a.	0
ZIFT	1	1	n.a.	0
Retrieve eggs	4	4	n.a.	0
Analyze embryos	3	2	n.a.	1
Transfer embryos	1	0	n.a.	1
Donate eggs	7	2	n.a.	5
Donate eggs — spouse	1	0	n.a.	1
Donate embryos	6	2	n.a.	4
Dispose of embryos	9	6	n.a.	3
Receive donor egg	6	2	n.a.	4
Selective reduction	1	1	n.a.	0
Cryopreserve embryos	9	5	n.a.	4
Thaw/transfer embryos	6	4	n.a.	2
Re-inseminate eggs	1	0	n.a.	1
Research	6	5	1	0

* Excludes solo practitioners.

Note: Discrepancies between the number of clinics using consent forms for specified procedures and the number offering the procedure (Table 1) may be due to a failure to provide the researchers with all forms, the use of a general or multi-purpose form, or the existence of a form for a procedure that is only in the planning stages.

n.a. — not available

Table 52. Topical Coverage of Print Patient-Education Materials Used in IVF/GIFT/ZIFT Programs in Teaching Hospitals, 1991

Procedure	Mentions	Purpose	Preparation	Minor risks	Major risks	Psychosocial	Who will do it	Aftercare	Recovery time	Costs	Options	Fetal risks	Multiple pregnancy
Egg retrieval	11	11	9	8	3	3	3	4	6	8	2		
Medications	11	11	4	7	8	6	2			9	3	4	6
Ultrasound	10	10	3	3		2	2			5		2	
Embryo transfer	10	10	5	5	3	8	3	9	7	7	3	6	7
Blood work	10	8	1	4		2				4			
Laparoscopy	8	7	4	3	3	1		4	4	1			
General anaesthetic	8	4	1			1	1	1	1	1			
Semen analysis	7	6	6	1	1					2			
Cryopreservation	5	5	4			3				2	3	2	2
Hysterosalpingogram	4	3	1	1				1	1				
Transfer to tube	3	3	2	2	2	1		1	1	2	3	1	1

Notes: 1. This table does not summarize the information in the few video tapes available from clinics, nor does it cover topics that were dealt with orally.
2. Materials were analyzed from all 11 programs in this category. Some procedures may not be applicable in some programs.

Table 53. Topical Coverage of Print Patient-Education Materials Used in AIH/TDI/IUI Programs in Teaching Hospitals, 1991

Procedure	Mentions	Purpose	Preparation	Minor risks	Major risks	Psychosocial	Who will do it	Aftercare	Recovery time	Costs	Options	Venereal infection	Fetal risks	Multiple pregnancy
TDI	13	8	7	4	4	6	3	1	1	5	2	5	5	
Semen analysis	13	9	8				1			1	1			
Laparoscopy	12	10	5	5	4			5	5	2				
Medications	11	9	1	6	6	2		2		4	4			6
Endometrial biopsy	10	9	3	3	1			2	1	1			1	
Hysterosalpingogram	10	8	3	4	1	1	1	3	1					
IUI/sperm wash	10	7	5	4	1	1	2	2	1	5	2			1
Post-coital test	9	8	6	2							1			
Blood work	9	7	2							1				
General anaesthetic	8	2												
Ultrasound	6	3	1							1				
AIH	2	2	2	1				1	1	1	2			0

- Notes:** 1. This table does not summarize the information in the few video tapes available from clinics, nor does it cover topics that were dealt with orally.
2. Materials were analyzed from 15 of the 18 programs in this group. Some procedures may not be applicable in some programs.

Table 54. Topical Coverage of Print Patient-Education Materials Used in Private Clinics and Non-Teaching Hospitals, 1991

Procedure	Mentions	Purpose	Preparation	Minor risks	Major risks	Psychosocial	Who will do it	Aftercare	Recovery time	Costs	Options	Fetal risks	Multiple pregnancy
Semen analysis	5	5	5										
Ultrasound	5	5	3							2			
Egg retrieval	5	5	4	4	3	1	1	3	3	3	1		1
Embryo transfer	5	4	4	5	2	3	1	4	5	4	4	3	4
TDI	5	5	1			3		1	1	3	3	1	
Blood work	5	5	3	1						3			
Medications	5	5	4	4	4	3	2			5	2	3	3
Cryopreservation	3	2	2	0						2	3	2	1
Donor ova/embryo	3	2		1	1								
Laparoscopy	3	2	2	1					1				
Hysterosalpingogram	1	1	1										

Notes: 1. This table does not summarize the information in the few video tapes available from clinics, nor does it cover topics that were dealt with orally.
 2. Materials were analyzed from 5 of the 6 programs in this group. Not all procedures are applicable in all programs.

Table 55. Information on Medications in Patient Education Materials in IVF/GIFT/ZIFT Programs in Teaching Hospitals, 1991

Medication	Mentions	Minor risks	Major risks	Multiple pregnancy	Fetal risks	Psychosocial	Costs
Clomiphene citrate (Clomid [®] , Serophene [®])	4	3	3	1	1	5	9
Menotropins (Pergonal [®])	8	5	6	2	4	7	9
Urofollitropins (Metrodin [®])	2	2	2	1		3	4
Progesterone	1			1		3	7
Profasi [®] , hCG	2				1	3	8
Estrogen/estradiol							8
Gn-RHa (Lupron [®] , Synarel [®] , buserelin)	5	1	1	1	2	4	6
Danazol [®]	1	1			1		1
Birth control pill							2

Gn-RHa — Gonadotropin-releasing hormone agonist

Note: This table does not summarize the information in the few video tapes available from clinics, nor does it cover topics that were dealt with orally.

Table 56. Information on Medications in Patient Education Materials in AIH/TDI/UI Programs in Teaching Hospitals, 1991

Medication	Mentions	Minor risks	Major risks	Multiple pregnancy	Fetal risks	Psychosocial	Costs
Clomiphene citrate (Clomid [®] , Serophene [®])	7	4		4	1	1	3
Menotropins (Pergonal [®])	9	8	6	8	2	1	3
Urofollitropins (Metrodin [®])	4	3	3	3	1	1	
Progesterone	3	1					
Profasi [®] , hCG	6	3	1				1
Estrogen/estradiol	1						
Gn-RHa (Lupron [®] , Synarel [®] , buserelin)	4	3	1				1
Danazol [®]	0						
Oral contraceptive	2						

Note: This table does not summarize the information in the few video tapes available from clinics, nor does it cover topics that were dealt with orally.

Table 57. Information on Medications in Patient Education Materials in IVF/GIFT/ZIFT Programs in Private Clinics and Non-Teaching Hospitals, 1991

Medication	Mentions	Minor risks	Major risks	Multiple pregnancy	Fetal risks	Psychosocial	Costs
Clomiphene citrate (Clomid [®] , Serophene [®])	4	3	1	4	1	2	1
Menotropins (Pergonal [®])	4	2	3	4	2	2	3
Urofollitropins (Metrodin [®])	3		1	2	1	1	1
Antibiotics	3	3					
Progesterone	3				1		2
Profasi [®] , hCG	4	2	2	2	2	2	2
Estrogen/estradiol	1		1				
Gn-RHa (Lupron [®] , Synarel [®] , buserelin)	1						
Danazol [®]	0						
Oral contraceptive	1	1					

Note: This table does not summarize the information in the few video tapes available from clinics, nor does it cover topics that were dealt with orally.

Appendix 2. Survey Materials

QUESTIONNAIRE FOR IVF-ET AND GIFT CLINICS

This questionnaire should be completed by the clinic director or his/her delegate and returned within two weeks of receipt.

*We encourage you to quote or refer to relevant patient material to answer any of the questions. **Please enclose copies of such documents** or identify them clearly if a copy has previously been sent to the Royal Commission.*

If you are unsure about any item on this questionnaire, please call Janice McLean at (613) xxx-xxxx or Tom Stephens at (613) xxx-xxxx, between 8:00 am and 6:00 pm Eastern time. Or fax us at (613) xxx-xxxx anytime.

Please return the completed questionnaire, collect, to the Commission in the courier envelope provided.

We plan to have a draft report by the end of March 1992 and will send you those parts which pertain to your clinic; we hope you will be able to review them for accuracy.

Thank you for your participation in this important study.

PLEASE NOTE THAT ALL QUESTIONS REFER TO THE CALENDAR YEAR 1991.

A. Clinic Description

1. During 1991, which of the following were available in this clinic?
Check [✓] all that apply.
 - ☐ IVF-ET
 - ☐ GIFT
 - ☐ ZIFT
 - ☐ receive donor egg/embryo
 - ☐ receive donor sperm
 - ☐ surrogacy
 - ☐ embryo genetic diagnosis
 - ☐ selective reduction
 - ☐ sex preselection with husband/partner's sperm
 - ☐ sex preselection with donor sperm
 - ☐ a choice of ovarian stimulation or natural cycle
 - ☐ other (specify:) _____
2. Were any of the procedures offered during 1991 discontinued recently?
 - ☐ NO
 - ☐ YES → Which? _____

3. Are you offering any procedures during 1992 that were not available in 1991?
- ☐ NO
- ☐ YES → Which? _____
4. Please describe the following practices in this clinic in 1991:
- maximum number of treatment cycles allowed per patient: _____
 - minimum time between treatment cycles: _____ months
5. In 1991, how did you define the objectives of this clinic?
- _____
- _____
6. In 1991, how did you describe to patients your success rates for ...
- IVF-ET? _____
 - _____
 - GIFT or ZIFT (if applicable)? _____
 - _____
 - _____
7. In 1991, how did you define...
- successful treatment? _____
 - pregnancy? _____
 - an IVF cycle? _____
 - a GIFT cycle? _____

B. Patient Admission

Once again, please feel free to refer to any patient materials that may be relevant.

8. Please describe the following criteria for accepting patients for IVF-ET treatment in this facility, and provide any necessary qualifications or elaboration (e.g., different criteria for different diagnoses).
- nature and duration of previous ART: _____
 - _____
 - duration of unexplained infertility: _____

9. How were the following factors considered in 1991 when deciding whether to provide IVF?

	NOT USED	POSSIBLE GROUNDS	PROBABLE GROUNDS
	FOR REFUSING		
Woman less than 18 years old	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Woman over 40 years old	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Unmarried with a partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Unmarried without a partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	NOT USED	POSSIBLE GROUNDS	PROBABLE GROUNDS
	FOR REFUSING		
Homosexual	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other living children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Low income	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologically immature	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physically disabled	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Below average intelligence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Doubtful parenting ability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Province of residence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Country of residence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Willingness to take part in research	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. In 1991, approximately how many requests for IVF did you...
- receive? _____
 - turn down? _____

11. If you do not accept a patient, do you refer them elsewhere for treatment?
- ☐ NO
- ☐ YES → Where? _____

C. Patient Records

12. Is your clinic currently supplying information to the Canadian IVF Registry?

☐ YES → When do you start? (mo/yr) _____

☐ NO → What needs to happen before you begin to participate in a Registry?

13. If patients received TDI or donor eggs in 1991, did you keep records for each donor of...

	NO	YES	N/A
Number of embryos transferred	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Number of pregnancies achieved	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Number of children born	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family genetic history	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Results of physical examination (lab tests)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Results of follow-up examinations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Results of follow-up lab tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14. Please indicate with a check in the box ☒ the status of the following information about patients.

If detailed records are kept, please provide a blank copy of a patient questionnaire or other relevant form, and indicate in what year you started keeping such records.

	NOT ASCERTAINED	SUMMARY INFORMATION	DETAILED RECORDS kept →since
Occupational history of woman	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> → 19____
Occupational history of man	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> → 19____
Contraceptive history of woman	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> → 19____
Contraceptive history of man	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> → 19____
Woman's history of STDs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> → 19____
Woman's history of sexual abuse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> → 19____

14. (cont'd)	NOT ASCERTAINED	SUMMARY INFORMATION	DETAILED RECORDS	kept →since
Woman's substance use and abuse <u>before</u> treatment (tobacco, alcohol, medications, illicit drugs)	[]	[]	[] → 19	____
Man's substance use and abuse <u>before</u> treatment (tobacco, alcohol, medications, illicit drugs)	[]	[]	[] → 19	____
Woman's substance use and abuse <u>during</u> <u>treatment</u>	[]	[]	[] → 19	____
Man's substance use and abuse <u>during</u> treatment	[]	[]	[] → 19	____
Other risks for female infertility	[]	[]	[] → 19	____
Other risks for male infertility	[]	[]	[] → 19	____
Health of mother for at least a year following treatment	[]	[]	[] → 19	____
Health of child resulting from treatment	[]	[]	[] → 19	____
Economic and psycho- logical impact for couple of treatment	[]	[]	[] → 19	____
Outcome of treatment <u>classified by diagnosis</u>	[]	[]	[] → 19	____

D. Patient and Outcome Data

15. Please provide the following statistics for the calendar year 1991. (If you have a statistical report covering all these items, you may attach it instead of completing these tables.)

For statistics which are not yet compiled, please indicate the date they would be available. If records are not maintained, indicate "NO DATA." If procedures are not offered, write in "N/A."

PROCEDURE	# PATIENTS, 1991	# PREGNANCIES, 1991 PATIENTS*
IVF-ET		
natural cycle		
stimulated		
GIFT		
natural cycle		
stimulated		
ZIFT		
Any of above with donor eggs/embryos		
Any of above with donor sperm		
* Report all pregnancies resulting from treatment in 1991, even if the pregnancy itself was confirmed in 1992.		

OUTCOME OF PREGNANCIES RESULTING FROM 1991 TREATMENT*	NUMBER
Total live births to patients	
singleton	
twins	
triplets	
quadruplets +	
Surrogacy births	
Ectopic pregnancy	
Spontaneous abortion	
Therapeutic abortion	
Stillborn	
Unknown outcome	
Pregnancy continuing	
* Report all pregnancies resulting from treatment in 1991, even if the pregnancy itself was confirmed in 1992.	

E. Patient Counselling

16. Please estimate the approximate percentage of your 1991 patients who received counselling (either in-house or through referral)...
- as couples _____ %
 - male partner only _____ %
 - female partner only _____ %
17. Who provided the counselling? *Check [✓] all that apply.*
- ☐ nurse
 - ☐ physician
 - ☐ psychiatrist
 - ☐ social worker
 - ☐ psychologist
 - ☐ peer support group
 - ☐ other: _____
18. Was there a psychologist/social worker or psychiatrist on staff in your clinic in 1991?
- ☐ NO
 - ☐ YES → ☐ full-time? ☐ part-time?
19. Please describe the purpose of counselling in this clinic for IVF-ET patients:
- _____
- _____
20. If you use donor sperm, eggs, or embryos for IVF-ET, do you normally advise parents to tell their offspring...
- ☐ nothing about having a different biological father or mother?
 - ☐ that they have a biological as well as a social father or mother?
 - or ☐ leave it to the parents' discretion.
21. In 1991, when was counselling normally provided in this clinic?
Check [✓] all that apply.
- ☐ before admission
 - ☐ during treatment
 - ☐ after treatment
22. Did you refer patients to counselling elsewhere in 1991?
- ☐ NO
 - ☐ YES → To whom? ☐ nurse
 - ☐ physician

22. (cont'd)

(Check [✓] all that apply.)

☐ psychiatrist

☐ social worker

☐ psychologist

☐ support group

☐ clergy

☐ other: _____

23. What were the criteria for referring patients to counselling 1991?

F. And Finally...

24. Please provide the name of this clinic's current:

- Medical director: _____
- Nurse coordinator: _____

25. For the person completing this questionnaire:

Name: _____

Contact telephone no: _____

Preferred time of the day/week to receive calls: _____

Thank you for your assistance with this study. Please return the questionnaire and any supporting documents in the courier envelope, or fax your completed questionnaire to: (613) xxx-xxxx.

QUESTIONNAIRE FOR FERTILITY CLINICS AND PRACTITIONERS (Not Offering IVF)

This questionnaire should be completed by the clinic director or his/her delegate and returned within two weeks of receipt.

*We encourage you to quote or refer to relevant patient material to answer any of the questions. **Please enclose copies of such documents** or identify them clearly if a copy has previously been sent to the Royal Commission.*

If you are unsure about any item on this questionnaire, please call Janice McLean at (613) xxx-xxxx or Tom Stephens at (613) xxx-xxxx, between 8:00 am and 6:00 pm Eastern time. Or fax us at (613) xxx-xxxx anytime.

Please return the completed questionnaire, collect, to the Commission in the courier envelope provided.

We plan to have a draft report by the end of March 1992 and will send you those parts which pertain to your clinic; we hope you will be able to review them for accuracy.

Thank you for your participation in this important study.

PLEASE NOTE THAT ALL QUESTIONS REFER TO THE CALENDAR YEAR 1991.

A. Your Clinic's Services

1. During 1991, which of the following were available in this clinic?
Check [✓] all that apply.
 - ☐ ovulation stimulation
 - ☐ treatment for male-factor infertility
 - ☐ AI with husband/partner's sperm
 - ☐ AI with anonymous donor's sperm
 - ☐ AI with known donor's sperm
 - ☐ AI with mixed partner and donor sperm
 - ☐ AI with more than one donor per cycle
 - ☐ IUI
 - ☐ peritoneal insemination
 - ☐ intrafallopian insemination
 - ☐ sex preselection with husband/partner's sperm
 - ☐ sex preselection with donor sperm
 - ☐ surrogate motherhood with donor sperm
 - ☐ other (specify:) _____
2. Were any of the procedures offered during 1991 discontinued recently?
 - ☐ NO
 - ☐ YES → Which? _____
3. Are you offering any procedures during 1992 that were not available in 1991?
 - ☐ NO
 - ☐ YES → Which? _____
4. Please describe the usual number of inseminations per treatment cycle in 1991 for...
 - donor sperm _____
 - unwashed husband/partner sperm _____
 - washed husband/partner sperm with IUI _____
5. In 1991, what method(s) did you use to time inseminations?

6. In 1991, when did you require the following for AI patients:

	Routinely or before Tx	→ After _____ cycles
basal body temperature charting	<input type="checkbox"/>	_____
hysterosalpingogram	<input type="checkbox"/>	_____
hormonal profile	<input type="checkbox"/>	_____
sperm-mucous (Kremer) test	<input type="checkbox"/>	_____
endometrial biopsy	<input type="checkbox"/>	_____
laparoscopy	<input type="checkbox"/>	_____
ovulation induction	<input type="checkbox"/>	_____
serial ultrasound	<input type="checkbox"/>	_____
sperm antibody evaluation	<input type="checkbox"/>	_____

7. In 1991, how did you define the objectives of this clinic?

8. In 1991, how did you describe to patients the success rates of...

• therapeutic donor insemination (TDI)? _____

• artificial insemination with husband/partner's sperm (AIH)? _____

• IUI? _____

9. In 1991, how did you define...

• successful treatment? _____

• pregnancy? _____

B. Patient Admission

10. Please estimate the approximate percentage of patients who requested AI in 1991 who were...

• married couples

_____ %

• unmarried heterosexual couples

_____ %

• lesbian couples

_____ %

• women without a partner

_____ %

• unknown status

_____ %

11. Please estimate the approximate percentage of patients who requested AI in 1991 because...
- male partner had no sperm _____%
 - male partner had poor quality sperm _____%
 - male partner had a vasectomy _____%
 - male partner had a genetic disorder _____%
 - male partner had chemo/radiotherapy _____%
 - male partner was HIV-positive _____%
 - male partner was impotent _____%
 - RH incompatibility between partners _____%
 - there was no male partner _____%
 - other (specify) _____%
12. What percentage of your 1991 couples with male-factor infertility received TDI? _____%
13. In 1991, approximately how many requests for AI did you...
- receive? _____
 - turn down? _____
14. How were the following factors considered in 1991 when deciding whether to provide AI?

NOT POSSIBLE PROBABLE
USED GROUNDS GROUNDS
FOR REFUSING

Woman less than 18 years old	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Woman over 40 years old	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Unmarried with a partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Unmarried without a partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Homosexual	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other living children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Low income	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologically immature	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physically disabled	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Below average intelligence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Doubtful parenting ability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Province of residence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Country of residence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Willingness to take part in research	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C. Records

15. In 1991, what was the maximum allowable number of...
- cycles per AIH patient? _____
 - cycles per TDI patient? _____
 - inseminations per donor? _____
 - pregnancies per donor? _____
16. In 1991, did you keep records that would permit you to identify the specific donor for any specific pregnancy?
- NO ☐ → Section D
- YES ☐ → How long do you maintain such records? _____ years
17. In 1991, did you keep records for each donor of...

	NO	YES	N/A
Number of women inseminated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Number of pregnancies achieved	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Number of children born	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family genetic history	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Results of physical examination (lab tests)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Results of follow-up examinations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Results of follow-up lab tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

18. What donor information would you provide to the following, if requested?

	None	Record w/o name	Record including name	Would forward request to sperm bank (if applicable)
Recipient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Recipient partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Offspring of insemination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Public Health Department	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Insurance company	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Research scientists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Judicial requests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

19. What information would you provide to a donor, if requested?
Check [✓] all that apply.

- ☐ Number of pregnancies
- ☐ Number of children
- ☐ Health of children
- ☐ Non-identifying information about recipient family
- ☐ Identifying information about recipient family

D. Donors

20. Please estimate the approximate percentage of all donor inseminations in 1991 in which you used...

- fresh sperm _____%
- frozen sperm _____%

21. Where were your donors for fresh sperm recruited in 1991?
Check [✓] all that apply.

- ☐ Medical students
- ☐ Graduate students
- ☐ Hospital personnel
- ☐ Other doctors
- ☐ Friends or relatives of patient
- ☐ Other: _____

22. Did you allow recipients to provide their own donors in 1991?

- ☐ NO
- ☐ YES → What % of all recipients requested this? _____%

23. Did you pay your donors in 1991?

- ☐ NO ☐ YES → How much? \$_____ per donation

24. Did you purchase sperm from a sperm bank in 1991?

- ☐ NO
- ☐ YES → What is the total cost to the patient of sperm per insemination? \$_____

25. What was your source for frozen sperm in 1991? _____

26. In 1991, which of the following donor characteristics were you normally willing to try to match, if requested?

	Willing	Not Willing
Age	<input type="checkbox"/>	<input type="checkbox"/>
Height	<input type="checkbox"/>	<input type="checkbox"/>
Weight	<input type="checkbox"/>	<input type="checkbox"/>
Eye color	<input type="checkbox"/>	<input type="checkbox"/>
Hair texture	<input type="checkbox"/>	<input type="checkbox"/>
Complexion	<input type="checkbox"/>	<input type="checkbox"/>
Body type	<input type="checkbox"/>	<input type="checkbox"/>
Race	<input type="checkbox"/>	<input type="checkbox"/>
Ethnic or national origin	<input type="checkbox"/>	<input type="checkbox"/>
Religion	<input type="checkbox"/>	<input type="checkbox"/>
I.Q.	<input type="checkbox"/>	<input type="checkbox"/>
Income	<input type="checkbox"/>	<input type="checkbox"/>
Educational attainment	<input type="checkbox"/>	<input type="checkbox"/>
Special abilities	<input type="checkbox"/>	<input type="checkbox"/>
Hobbies or interests	<input type="checkbox"/>	<input type="checkbox"/>
Other: _____	<input type="checkbox"/>	<input type="checkbox"/>

27. Who normally makes the final selection of a donor? _____

28. To screen potential sperm donors in 1991, did you ask about.

	NO	YES
• their sexual orientation?	<input type="checkbox"/>	<input type="checkbox"/>
• their sexual activity?	<input type="checkbox"/>	<input type="checkbox"/>

29. For a genetic screen of potential sperm donors in 1991, did you request...

	NO	YES
• a chromosomal analysis (karyotype)	<input type="checkbox"/>	<input type="checkbox"/>
• genetic History	<input type="checkbox"/>	<input type="checkbox"/>
• other: _____	<input type="checkbox"/>	<input type="checkbox"/>

30. In 1991, did you test potential sperm donors for...

	NO	YES
Chlamydia	<input type="checkbox"/>	<input type="checkbox"/>
Cytomegalovirus	<input type="checkbox"/>	<input type="checkbox"/>
Ejaculate C+S	<input type="checkbox"/>	<input type="checkbox"/>
Gonorrhoea	<input type="checkbox"/>	<input type="checkbox"/>
Hepatitis A&B	<input type="checkbox"/>	<input type="checkbox"/>
Herpes	<input type="checkbox"/>	<input type="checkbox"/>
HPV	<input type="checkbox"/>	<input type="checkbox"/>

30. (cont'd)

	NO	YES
Syphilis	<input type="checkbox"/>	<input type="checkbox"/>
Trichomoniasis	<input type="checkbox"/>	<input type="checkbox"/>
Tuberculosis	<input type="checkbox"/>	<input type="checkbox"/>
HIV-1 & HIV-2	<input type="checkbox"/>	<input type="checkbox"/>

→ with periodic retesting?
☐ NO
☐ YES → How often?

E. Patient and Outcome Data

31. Please provide the following statistics for the calendar year 1991.
(If you have a statistical report covering all these items, you may attach it instead of completing these tables.)

For statistics which are not yet compiled, please indicate the date they would be available. If records are not maintained, indicate "NO DATA". If procedures are not offered, write in N/A.

PROCEDURE	# PATIENTS, 1991	# PREGNANCIES, FOR THESE PATIENTS*
AIH		
TDI		
IUI		
AIH & TDI		
Sex preselection		
Surrogacy		
* Report all pregnancies resulting from 1991 treatment, even if they were confirmed in 1992.		

OUTCOME OF PREGNANCIES RESULTING FROM 1991 TREATMENT*	TDI	AIH
Total live births		
singletons		
multiple births		
Ectopic		
Spontaneous abortions		
Therapeutic abortions		
Stillborn		
Serious anomalies		
Low birth weight		
Pre-term delivery		
Unknown outcome		
Pregnancy continuing		
* Report all pregnancies resulting from 1991 treatment, even if they were confirmed in 1992.		

F. Patient Counselling

32. Please estimate the approximate percentage of your 1991 patients who received counselling (either in-house or through referral)...
- as couples _____ %
 - male partner only _____ %
 - female partner only _____ %
33. Who provided the counselling? Check [✓] all that apply.
- [] nurse
 - [] physician
 - [] psychiatrist
 - [] social worker
 - [] psychologist
 - [] peer support group
 - [] other: _____
34. Was there a psychologist/social worker or psychiatrist on staff in your clinic in 1991?
- [] NO
 - [] YES → [] full-time? [] part-time?

35. Please describe the purpose of counselling in this practice for:

- AIH _____

- TDI _____

36. Do you normally advise parents to tell their TDI offspring...

- ☐ nothing about having a different biological father?
- ☐ they have a biological as well as a social father?

or ☐ leave it to the parents' discretion.

37. During 1991, when was counselling normally provided in this clinic?
Check [✓] all that apply.

- ☐ before admission
- ☐ during treatment
- ☐ after treatment

38. Did you refer patients to counselling elsewhere in 1991?

☐ NO → Section G

☐ YES → To whom?

(check [✓] all that apply.)

☐ nurse

☐ physician

☐ psychiatrist

☐ social worker

☐ psychologist

☐ support group

☐ clergy

☐ other: _____

39. What were the criteria for referring patients to counselling in 1991?

G. And Finally...

40. Please provide the name of this clinic's current:

- Medical Director _____
- Nurse Coordinator _____

41. For the person completing this questionnaire:

Name: _____

Contact Tel. no.: _____

Preferred Time of the day/week to receive calls: _____

Thank you for your assistance with this study. Please return the questionnaire and any supporting documents in the courier envelope to:

Clinic Survey
Royal Commission on New Reproductive Technologies
66 Slater Street, 8th floor
Ottawa K1P 5H1

Or fax your completed questionnaire to: (613) xxx-xxxx

INTERVIEW GUIDE: FERTILITY CLINICS

Clinic _____ Date: _____

A. Introduction

1. Background: overview of Royal Commission on New Reproductive Technologies research, this and other projects.
2. Confirm: ☐ time and persons available for interview
☐ whether anyone cannot stay for the duration
☐ whether anyone else to join partway through
3. Objectives of this visit:
☐ to provide any needed clarification on the questionnaire
☐ ask some additional questions about clinic policies and practices
☐ ensure that we have a complete set of 1991 patient materials
☐ update other information received to date
☐ see some of the facilities.
4. Note: telephone follow-up is possible if time insufficient.

B. Follow-up on Completed Questionnaires

If questionnaire has not been completed, these questions may be asked later over the phone. When is the questionnaire expected? _____

If questionnaire has been received, review before the interview for the following items and note any need for follow-up. If none needed, mark n/a.

5. Discontinued Practices (IVF 2 and AI 2): ☐ NONE ☐ SOME

If any, get reasons: _____

6. Timing of IVF cycles (IVF 4): Does answer describe the actual practice, or just the policy?

☐ practice ☐ policy only → ask:

max # cycles: _____ min. interval: _____

7. Success Rates (IVF 6 and AI 8): *confirm*: based on the clinic's own experience?

☐ YES → for what time period? _____ years

☐ NO → on what basis? _____

8. Patient Assessment (IVF 9 and AI 14):

If "physically disabled" is a possible or probable basis for refusing AI, how severe must the disability be? *(Get an example.)*

9. Who establishes the criteria for deciding on admissions?

☐ team decision

☐ medical director

☐ counsellor

☐ other: _____

10. Who actually makes the decision on whether or not to accept a woman/couple into treatment?

☐ team decision

☐ medical director

☐ counsellor

☐ coordinator

☐ other: _____

11. Refusing Patients (IVF 10 and AI 13):

Is there any avenue of appeal for a patient who is turned down for any reason?

☐ NO ☐ YES → Describe procedure: _____

12. Patient Assessment (IVF 14):

If "other risks" are ascertained (male or female), check for blank patient questionnaire. If none, record details:

13. Other Admission Criteria (IVF 9 and AI 14):

Was there a waiting list in 1991 for...

- initial assessment? ☐ NO ☐ YES → how long? _____ wks.
- AI? ☐ NO ☐ YES → how long? _____ wks.
- IVF? ☐ NO ☐ YES → how long? _____ wks.

If a waiting list for any of the above, ask:

If a couple were willing to pay, or perhaps to make a donation to the clinic's research fund, would this provide them with faster access to fertility services?

☐ NO ☐ YES → Describe: _____

14. Screening Donors (AI 30):

For HIV without retesting, is there any mechanism for finding out about donors who have late-onset HIV? (*Get details.*)

15. Sharing Donor Records (AI 18):

Ask for a brief rationale for the policy on record sharing: why are records (not) provided when requested?

16. Are records for clinic patients kept separate from hospital records, or integrated with them?
- ☐ kept separate
- ☐ integrated
- ☐ other: _____
17. Sources of Counselling (AI 33 or IVF 17):
- ☐ none or one
- ☐ more than one → how are counselling responsibilities shared?
- _____
- _____
18. Purpose of Conselling (IVF 19 and AI 35): *Ask about the content of counselling if not clear from the answers provided about purpose.*
- _____
- _____
19. Pre-Admission Counselling (IVF 21 and AI 37):
- If counselling is required before treatment, is the purpose to screen prospective clients?
- ☐ YES ☐ NO → What is the purpose? _____
- _____
- _____

C. Informed Consent

20. Can you describe what happens if a woman/couple is accepted into treatment, but they later decide they do not want to give consent for a specific procedure?
- ☐ alternative procedure offered, if available
- ☐ they are referred elsewhere
- ☐ they are dropped from treatment, without referral
- ☐ other: _____
21. What happens if a couple revokes consent once it has been given?
- ☐ alternative procedure offered, if available
- ☐ they are referred elsewhere
- ☐ they are dropped from treatment, without referral
- ☐ other: _____

22. With regard to obtaining informed consent, could you tell us...
- who provides oral information to the couple (to supplement the written)? _____
 - your policy on describing risks? _____
 - your policy on providing choices? _____
 - when you ask for informed consent, that is, how much time the couple has to think about choices and risks? _____
 - what opportunities the couple have to discuss between themselves before giving consent? _____
 - how you deal with patients who don't speak English/French? _____

D. Other Clinic Procedures

23. IVF Clinic? ☐ YES ☐ NO → next page
- Do you offer couples a choice as to...
- | | NO | YES → get details |
|-----------------------------------|--------------------------|--------------------------|
| • # of ova to be fertilized? | <input type="checkbox"/> | <input type="checkbox"/> |
| • # of embryos to be transferred? | <input type="checkbox"/> | <input type="checkbox"/> |
| • # of embryos to be frozen? | <input type="checkbox"/> | <input type="checkbox"/> |
24. Do you routinely seek feedback from all patients on their satisfaction with treatment?
- ☐ NO → Which patients, if not all? _____
- ☐ YES → Get details on procedures: _____
25. Do you get enquiries about preimplantation diagnosis (i.e., diagnosis of genetic disorders in the very early embryo) from patients or their physicians?
- ☐ NO ☐ YES → about how many in 1991? _____

26. Do you employ preimplantation diagnosis in relation to your program of assisted human reproduction?

☐ NO ☐ YES → Do you anticipate doing so within the next 5 years?

☐ NO ☐ YES → Will you use the resources of a molecular genetics/prenatal diagnosis centre?

☐ NO ☐ YES → Which one? _____
☐ or employ a molecular geneticist within your own centre?

27. If the Commission had a need for financial information in a follow-up inquiry, who would be the best person to contact for that?

name: _____

position: _____

tel. no.: _____

E. Observations

28. Organization of records (Patient Survey):

29. Patient Education Materials: Refer to list of material received; verify completeness and currency

30. Physical layout of clinic:

☐ space for couples to talk: _____

☐ counselling space: _____

☐ proximity to maternity ward: _____

☐ baby pictures on display: _____

☐ sperm-production facility: _____

31. Names/positions of staff present (note if less than entire interview):

32. Duration of interview: _____

33. Visit by: LB JM TS RCNRT staff: _____

F. Follow-up on Outstanding Questionnaire(s)

34. Ask if any problems understanding questions, offer to clarify as needed

35. Check re: statistical reports, need for additional time, confirm expected completion date
36. If \$ needed, offer up to \$250 for staff overtime, payable upon presentation of an invoice to TS

G. Other Observations and Notes

(Emerging Issues, new developments, e.g., IVF surrogacy, other new procedures)



LA SOCIÉTÉ CANADIENNE DE FERTILITÉ ET D'ANDROLOGIE
THE CANADIAN FERTILITY AND ANDROLOGY SOCIETY

February 5, 1992

Dear Colleagues:

As you are aware there have been many changes in the management of any infertile couple in recent years and these changes have occurred as a result of advances in the new reproductive technologies. These advances have brought many benefits to institutions and universities as well as personal opportunities and academic enhancements.

The Royal Commission on New Reproductive Technologies is reminding us that these benefits bring with them responsibilities not only to our patient's care but also to society in general. The Board of the Canadian Fertility and Andrology Society has extended an unanimous vote of support in the activities of the Royal Commission on New Reproductive Technologies and on behalf of the Board of the Canadian Fertility and Andrology Society I am requesting that you assist the Royal Commission in the completion of its mandate by the completion of these important questionnaires.

Thank you for your consideration of this very important task. Best personal regards.

John F. Jarrell, President
Canadian Fertility and Andrology Society

JJ/gb

THE SOCIETY OF OBSTETRICIANS AND GYNAECOLOGISTS OF CANADA
LA SOCIÉTÉ DES OBSTÉTRICIENS ET GYNÉCOLOGUES DU CANADA
1785 ALTA VISTA DRIVE, SUITE 102, OTTAWA, ONTARIO K1G 3Y6 613-521-4192
FAX 613-521-4314



Office of the President
Bureau du Président

February 6th 1992.

Dear Colleagues:

The Royal Commission on New Reproductive Technologies is requesting your assistance in completion of the enclosed survey by all IVF clinics.

The SOGC has had the opportunity to present to the Royal Commission on numerous occasions with the intent of facilitating understanding about the medical aspects of New Reproductive Technologies including counselling and social issues of relevance.

The Executive of SOGC has recently confirmed its unanimous support for the Royal Commission on New Reproductive Technologies. Completion of these questionnaires will facilitate an objective assessment of the services provided by IVF clinics in Canada. This is important if we are to maintain our credibility.

On behalf of SOGC Executive and Council, I would urge you to assist in the completion of this important project.

Thank you for your co-operation.

Yours with kind regards,

Dorothy Shaw
President, SOGC.

Royal Commission on
New Reproductive Technologies



Commission royale sur les
nouvelles techniques de reproduction

February 10, 1992

Dear Colleague:

I am writing to you to request your assistance regarding a survey of fertility practitioners which the Royal Commission on New Reproductive Technologies (RCNRT) is conducting.

During the public hearings phase of the Commission's mandate, we learned something about fertility clinics from patients, practitioners and the general public. For a more complete picture it is important for the Commissioners to have comprehensive data and information obtained directly from practitioners for their consideration.

In July 1991, in response to our request to fertility clinic directors, we received some very informative patient education material. However, the picture remains incomplete in some important respects. For example, we need to learn more about patient counselling and certain clinic policies, and we need to have consistently defined statistics for 1991. Thus we seek your cooperation in the timely completion of the enclosed questionnaire about your practice.

The questionnaire is not very long, and our hope is that it can be completed within two weeks of receipt and returned in the envelope provided or by fax. A response from each practitioner in this survey is vital to enable the RCNRT to fulfil its obligation under its mandate and to provide the most accurate information possible. We also hope that by making the results of this undertaking available to practitioners, the Commission will be contributing to your work in a meaningful way.

We seek to have 100% participation in this important study, and we thank you for your assistance.

Yours sincerely,

Patricia Baird.

Patricia A. Baird, M.D., C.M., FRCPC, F.C.C.M.G.
Chairperson

Royal Commission on
New Reproductive Technologies



Commission royale sur les
nouvelles techniques de reproduction

February 11, 1992

Dear Administrator:

Update on Commission's Activities

I am writing to you again to request your assistance regarding a survey of fertility clinics and their patients which the Royal Commission on New Reproductive Technologies (RCNRT) is conducting. Last month the RCNRT wrote to request your assistance with a study of research on human embryos and fetal tissue. We thank you for your help with that study. The high response rate in the study means that both the research community and the Commission will have valuable data on which to deliberate.

During the public hearings phase of the Commission's mandate, we learned something about fertility clinics from patients, practitioners and the general public. For a more complete picture it is important for the Commissioners to have comprehensive data and information obtained directly from clinics and patients for their consideration.

Fertility Clinic Survey

In July 1991, in response to our request to fertility clinic directors, we received some very informative patient education material. However, the picture remains incomplete in some important respects. For example, we need to learn more about patient counselling and certain clinic policies, and we need to have consistently defined statistics for 1991. We also need to understand patients' perceptions of their experience while receiving treatment. Thus we seek your cooperation in the timely completion of the enclosed questionnaires about clinic practices, and in the distribution of a **related questionnaire for patients**, to follow shortly.

We have provided two questionnaires for the clinic survey which we ask you to forward to the appropriate clinic director(s) for his or her priority attention. The blue one is for IVF clinics and the yellow one is for other fertility services such as artificial insemination. Neither questionnaire is very long, and our hope is that each will be completed within two weeks and returned in the envelopes provided or by fax.

As there are only 27 fertility clinics in Canada, a response from every one is vital, to enable the RCNRT to fulfil its obligation under its mandate and to provide the most accurate information possible. We also hope that by making the results of this undertaking available to the fertility clinics involved, the Commission will be contributing to your work in a meaningful way.

We seek to have 100% participation in this important study, and we thank you for your assistance.

Fertility Clinic Patient Survey

Further information on this parallel survey should be sent to you within the next two weeks.

Yours sincerely,

Patricia Baird.

Patricia A. Baird, M.D., C.M., FRCPC, F.C.C.M.G.
Chairperson

Appendix 3. Readability Analysis¹

Reading Level

Overall, the reading level of the patient material analyzed for this project was unacceptably high, even assuming that the education level of the patients might be above that of Canadians as a whole.

In particular, the reading level of the consent forms was unrealistically high. Fifteen of the 16 consent forms had a reading level of grade 14 or higher. Of the 26 patient education items, 11 had a reading level of grade 14 or higher. Not only are these materials well beyond the education level of most Canadian adults, it is not unusual for people to have a reading level lower than their level of education.

The ability of a reader to absorb and use information is related to a variety of factors, including stress, anxiety, background knowledge, personal experience, and the type and extent of assistance available to support the printed materials.

People have more difficulty in absorbing and understanding information when they are in an anxious or stressful situation. For many women and couples, acknowledging a fertility problem, seeking medical assistance, and participating in an IVF or AI program would be stressful and anxiety-producing. Most would have little background knowledge about or personal experience with the procedures that they might undergo.

Considering the reading level of the materials, the lack of background knowledge of the reader, and the levels of stress likely to be involved, there is cause to question the degree to which program participants would be able to understand exactly what they were consenting to. For these reasons, extra care should be taken to ensure that the reading levels of both consent forms and patient education materials are somewhat lower than the education levels of the clients.

It must be acknowledged that the nature of infertility requires the use of many polysyllabic words. For example, *insemination*, *Pergonal*[®], *fertilization*, and *embryo* are all used frequently, and for the most part unavoidably: part of the purpose of the patient education materials is to familiarize clients with this technical vocabulary, and the purpose of consent forms is to obtain the patient's agreement to treatments involving these terms.

Although readability formulas have not been designed to take specialized health or legal vocabularies into account, the SMOG formula is particularly effective with health-related materials precisely because it highlights specialized vocabulary and allows writers to identify problem areas, choose words and terms carefully, and develop ways to deal with specific issues. It would be difficult to reduce the SMOG score on this kind of material much below grade 10, without eliminating most of the technical

¹

Adapted from a report prepared for this project by Janis Wood Catano

vocabulary. However, the materials could still be made more readable and, once the essential technical vocabulary has been identified, efforts could be made to define terms clearly and to make all other parts of the document as uncomplicated as possible.

It should also be remembered that the number of syllables is not the only index of the difficulty of words. For example, *in vitro* contains no polysyllables, but that does not guarantee that all readers will comprehend its meaning. In a study of unfamiliar words used in diabetes literature, Thrush and Lanese found that while these kinds of topic-specific words accounted for only 20 percent of unfamiliar words in the documents they examined, they accounted for 66 percent of the unfamiliar occurrences and thus contributed disproportionately to the reading difficulties of most of the materials.¹³

Although many of the materials examined in this analysis make some attempt to define new words in context, only one of them contains a glossary. In this case, it does not offer much assistance to the reader, as the definitions themselves are extremely technical and complex. In general, however, defining new or technical terms in context, as well as in a word list using common, everyday language, helps to increase the reader's familiarity and comfort with the terms.

Writing Style

Many of the factors that can reduce reading levels and increase readability are related to writing style. The writing style encompasses all aspects of the way in which the content is presented. Style includes the material's point of view, its tone of voice, and its use of language. Style is the overall impression or feeling that the material evokes in the reader.

Style is in turn made up of many smaller factors, for example, the use of active or passive voice, the use of concrete or abstract information, and the use of longer or shorter sentences.

The following samples contain the first two sentences from each of several patient education materials from different clinics. These two sentences may be the first written contact the client has with the program. Consider the feelings the different styles are likely to evoke in the reader.

Sample 1a:

You have come to find out why you do not have a baby or for correction of whatever may be the cause of failure. It will help us and you if you understand the procedures that are necessary to enable us to help you.

Sample 1b:

Our programmes are designed to achieve as good a pregnancy chance as possible, but also to be as safe for the mother and child as can be done. THE NOTES WRITTEN IN CAPITAL ARE THE PARTS YOU ARE REQUESTED TO DO AND YOUR FOLLOWING THESE ARE VERY MUCH EXPECTED OF YOU TO ACHIEVE THE ABOVE GOALS.

Sample 1c:

You are now ready to start your course of treatment. We appreciate that this will be a stressful and anxious time for you both and hope that these short notes will go some way to reducing your level of stress.

None of these three samples has an unusually high reading level. None uses difficult, complex language or technical terms. However, each has a distinctive style and tone of voice that convey very real attitudes toward the reader. The empathy and acknowledgment of the patients' needs and feelings shown in Sample 1c are the exception rather than the rule.

Sample 1a shows no respect for either the feelings or the intelligence of the readers. In two brief sentences it makes it very clear that there is a failure on the part of the patient and that the solution lies with the clinic. There is no sense of mutuality, of consultation, of participation, or of involvement on the part of the client. The patient's role is to read the material to enable someone else to remedy her "failure."

Sample 1b is written in an extremely directive style. Again, in only two sentences, it becomes very clear that the patient's role in this process is to read and obey. The implication is that the program is the patient's last hope and she must do what she is told.

Sample 1c is the only one that reaches out to the patients, acknowledging and empathizing with their anxiety and pain. It addresses the readers as people, not just as clinical subjects.

With few exceptions, the patient education material submitted to this study was written in a very clinical and directive style. The style conveyed two messages: the clinical, technical nature of the descriptions of drugs and procedures indicated to the reader that fertility treatment was complicated, scientific, and not something that they could hope to understand. The directive tone indicated that whether or not they understood, they must do what they were told.

The use of a clinical, technical style in conveying medical information is not unusual in patient education materials. It reflects the kind of technical, scientific writing with which most health and medical professionals are comfortable and familiar. It uses the passive voice, deals with facts rather than feelings, and is concerned primarily with transmitting information rather than experience.

The directive tone is less usual. While it is apparent from the content of the patient education materials that the processes being described are complex and often rely on precise timing, the material also makes it clear that the onus is on the patient to conform to the protocol. If she does not, she is dropped from the program.

There is no style of writing that is appropriate for all circumstances or audiences. While a clinical style is certainly effective for communication between clinicians, it is not the style most appropriate for use in patient education materials. A more relaxed, informal style would be easier for most people to read and understand.

A Preferred Style

The most direct approach to a less formal style is to write in a conversational tone, that is, to write as though the writer were speaking to the reader and the reader was someone whom the writer cared about. A conversational style reflects an exchange between equals. It does not imply that the writer is giving orders to the reader.

The use of a conversational style has a direct impact on the readability of the material:

- **Sentence lengths become more variable.** While short sentences are easier to read than long sentences, material that is written using only short sentences can sound choppy, childish, and patronizing. On the other hand, material that uses only long, complex sentences is difficult to follow and understand. Spoken sentences are usually shorter and less complex than written ones. The ebb and flow of conversation is also conducive to the use of many different kinds and lengths of sentences.
- **The active voice is used more frequently.** In a conversation, it is natural to address a topic directly. The passive voice is less readable because it puts the subject closer to the end of the sentence; the reader has to read the entire sentence to get to the point (e.g., "Occasionally pain is felt by the patient at the site of the injection" is passive; "You might feel some pain where the needle went in" is active).
- **The tone becomes warmer and more personal.** Patient education materials often refer to *the patient*. It is difficult to imagine a conversation in which a clinician would address a client as *the patient*. It would be natural to use the word *you*. The use of *you* has the additional advantages of adding warmth and human interest to the material and enabling the reader to relate personally to the information. It also facilitates the process of presenting information from the patient's point of view, that is, focussing less on the details of the procedure and more on what the mother feels or experiences in relation to the procedure.

The following passages illustrate additional points about writing style. Each of the passages in the first group of samples describes the drug Pergonal[®]. These samples illustrate several different approaches to describing a medication.

Sample 2a: In this sample, very technical information is presented in a very clinical style. It introduces more difficult concepts than it explains.

Pergonal[®] (hMG) and Metrodin[®] are commercially available preparations of LH and FSH extracted from the urine of post-menopausal women. These hormones are normally secreted by the pituitary gland and will stimulate the follicles of your ovaries to mature and ripen.

Sample 2b: This sample breaks the information into smaller units, but is still very clinical in content and tone. Will the reader need to know or be able to understand the pharmacological information provided?

Pergonal is a purified preparation of gonadotropins extracted from the urine of post-menopausal women. Each ampoule of Pergonal® contains 75 I.U. of follicle-stimulating hormone (FSH) and 75 I.U. of luteinizing hormone (LH).

When administered, Pergonal® produces ovarian follicular growth in women who do not have primary ovarian failure.

Sample 2c: This sample is a bit more related to the reader. It tries to define some terms, but then introduces *estradiol*, another new, undefined word.

Pergonal (hMG) is a natural product of a woman's body. It is the hormone (chemical material) that is produced by the pituitary gland which stimulates the ovaries to cause ovulation and produce estradiol.

Sample 2d: This very direct and basic sample tries to give the information that the patient needs as clearly as possible. Using the word *eggs* instead of *oocytes* would increase clarity.

Human menopausal gonadotropin (hMG) is a combination of two hormones which normally are produced by the pituitary gland. These hormones help the oocytes to grow.

Sample 2e: This shows how sample 2d could be rewritten to be as direct and conversational as possible.

Pergonal is a combination of two hormones that help eggs to ripen in your ovaries. Normally, your own body produces these hormones.

The five passages above illustrate the importance of considering the content in relation to what the reader wants or needs to know. The first two passages contain information that is primarily of interest to clinicians. They contain technical information, use formal phrasing, and require some background knowledge on the part of the reader. The subsequent passages are progressively less formal and provide direct information in a form that most readers would find easier to read and use.

Point of View

The passages in the next set of samples show the influence of point of view on the content of material. Different kinds of information become important depending on whose point of view is being considered — the reader directly, or some hypothetical patient.

The following samples illustrate two possible ways to address the emotional and psychological issues arising from AI.

Sample 3a: This sample deals with the issues indirectly. It suggests “time and counselling” but offers no specific advice, information, or validation of feelings.

The technical aspects of A.I.D. are straightforward but ethical, moral, legal and religious dilemmas remain. The couples approaching A.I.D. need time and counseling to make their decision which must be an informed decision.

Sample 3b: This sample contains the introductory sentences from an item concerned solely with providing information and reassurance to couples facing the issues raised by AI. It addresses concerns directly and offers validation and support for a range of feelings and reactions.

For the couple attempting to achieve pregnancy, insemination raises complex issues and feelings, particularly when donor semen is to be used. As with other options available to infertile couples, it can help to know how other husbands and wives have reacted to these choices. The isolation that surrounds infertility may mean you've had few sources of support and information.

Readability of Legal Language

The issues related to the writing style of the consent forms are somewhat different from the style issues of the patient education materials. Because consent forms are essentially legal documents, it is understandable that the writers should exercise care that all legal requirements are covered. However, the primary purpose of informed consent is to provide sufficient information to enable readers to understand the procedure to which they are consenting. If the reader cannot understand, the reader cannot consent.

The following samples illustrate how extremely legal language can obscure the issue of consent, as well as how the same information can be conveyed more clearly.

Sample 4a: This extremely legalistic and difficult sample has a reading level of grade 27.

WE HEREBY ACKNOWLEDGE AND AGREE AS FOLLOWS:

1. That no representations, warranties, provisos, or guarantees as to the number of children, the sex, physical or mental abilities or characteristics, the presence or absence of physical and mental disabilities, diseases, congenital defects or any other human characteristics whatsoever of any child or children resulting from the said inseminations have been made to us by the Hospital, its agents, servants, employees or any attending physician, surgeon or any other medical attendants using the said Hospital's facilities (hereinafter collectively termed "Hospital Personnel").

Sample 4b: This sample is much clearer, but is by no means easy. The reading level of this item is grade 18.

1. We have been fully informed that a pregnancy which may result from such artificial insemination has the same possibility of resulting in an extra-uterine pregnancy, miscarriage, fetal malformation, complication of childbirth or delivery, and other adverse consequences as any normally achieved pregnancy ...

3. We fully realize that although it is the intention of Drs _____, _____, _____ and assistants to match the donor's physical appearance (including race) as closely as possible to the husband, wife or both, this cannot be guaranteed.

Sample 4c: This sample is briefer and deals with fewer issues.

2. We rely on the judgment and discretion of Dr. _____ to select a donor whose characteristics are compatible with ours. However, we fully understand that neither the donor nor Dr. _____ can be held responsible for the physical or mental characteristics of any children so produced.

Visual Appeal

The visual appeal of a piece of printed material is made up of many small points, including the size of type, the style of the typeface, the length of the lines of type in relation to the type size, the colours of the paper and ink, the amount of type that appears on each page, the way in which these blocks of type are arranged, the amount of empty space on the page, and the size and shape of the document. All of these features contribute to an overall impression that influences the reader's perception as to whether or not the material is readable.

Earlier in this report, conversational writing style was described as material written "as though the writer were speaking to the reader and the reader was someone the writer cared about." This approach is relevant to visual style as well. It is not only important that the material *sound* as though the producers care; it must also *look* as though the producers care.

Visual appeal was another weak point in the material submitted to this survey, both for the consent forms and for the patient education material. The most common problems were smudged, blurry type; an overall messy, careless appearance; crowded, dense-looking text; and justified rather than ragged-right typesetting.

Most of the material was produced on 8½-by-11 inch, letter-size paper. This seems to have been a matter of convenience and is not necessarily a problem. However, little effort was made to capitalize on the advantages of this large page size. For the most part, the material was simply typed and photocopied, with apparently little thought given to appearance or presentation.

Most of the problems related to visual appeal can be easily and inexpensively corrected. The letter-size page format can be used to good advantage by employing a large, easy-to-read typeface; ample white space; ragged-right typesetting; and bold type for emphasis.

In two cases, considerable care had been taken with production. In each case, basic descriptive information about the treatment programs had been professionally produced in booklet format. Both items were attractive, illustrated, well designed, and well produced. They conveyed a feeling of care and concern before the patient even began to read, adding a great deal to the overall readability of the material.

Recommendations

While most of the material analyzed was difficult to read, several of the items had positive features that could provide the basis for constructive change. For example, much of the material was well organized and thorough. In many cases, relatively minor and low-cost changes would result in a vast improvement in the readability of the material. In addition, there are several excellent models that could offer guidance in making changes to existing materials. These models are available in separate binders.

1. **All existing materials and any new or revised materials should be pretested with clinic patients.** Pretesting with the intended audience provides immediate feedback on the readability, clarity, credibility, usefulness, and consistency of the material as perceived by the people who will be using it. Pretesting need not be elaborate or expensive, yet it provides invaluable information on the content and presentation of patient education materials.
2. **Consultation with professional writers and designers should be a part of the development of new materials.** In the two instances where professionals appear to have been consulted, the readability of the resulting material is far better than in most other examples. In many cases, brief consultation with an editor or designer would make an enormous difference in the quality and readability of the materials. Several clinics or programs could consider pooling their resources, which would allow careful development of the content, adequate testing of the resource, and better production quality than might be possible for individual clinics.

Acknowledgments

Thanks are owed to a number of people in various organizations for their contributions to this study, especially during the crucial phases of design and data collection: to Janet Hatcher Roberts and Jennifer Kitts for their knowledge, enthusiasm, and skilled management of the contract for this study on behalf of the Royal Commission; to Dr. Rona Achilles, Dr. John Jarrell, Dr. Art Leader, Michelle Ann Mullen, Chris Newton, Sue Ward, and Linda Williams, for helping to identify information needs and appropriate methods; to Dr. John Jarrell and Dr. Art Leader for reviewing the questionnaires through several drafts; to Dr. Dorothy Shaw and Dr. John Jarrell for encouraging the members of the Society of Obstetrics and Gynaecologists of Canada and the Canadian Fertility and Andrology Society

to participate in the study; and especially to the directors and staff of the 38 programs and the 11 solo practitioners who generously gave their time in answering the questionnaires and participating in the interviews.

Notes

1. Fourteen individual members of the Canadian Fertility and Andrology Society were identified as probable high-volume users of frozen sperm by Society representatives.
2. In this study, these clinics were Institut de Médecine de la Reproduction de Montréal inc.; Toronto Fertility Sterility Institute; C.A.R.E. Centre, Mississauga, Ontario; and IVF Canada, Scarborough, Ontario.
3. Visits were made by various combinations of Janice McLean, Lucie Brunet, Thomas Stephens, and Rona Achilles.
4. F. Baylis, "Assisted Reproductive Technologies: Informed Choice," in *New Reproductive Technologies: Ethical Aspects*, vol. 1 of the research studies of the Royal Commission on New Reproductive Technologies (Ottawa: Minister of Supply and Services Canada, 1993).
5. G.H. McLaughlin, "SMOG Grading — A New Readability Formula," *Journal of Reading* 12 (1969): 639-46.
6. National Cancer Institute, Office of Cancer Communications, *Readability Testing in Cancer Communications: Methods, Examples and Resources for Improving the Readability of Cancer Messages and Materials* (Washington, DC: Department of Health, Education, and Welfare, 1979).
7. J.W. Catano and M.J. Breen, "Developing Health Teaching Materials That People Can Read," *Literacy* 12 (1)(1987): 23-30.
8. See SPR Associates, "An Evaluation of Canadian Fertility Clinics: The Patients' Perspective," in *Treatment of Infertility: Current Practices and Psychosocial Implications*, vol. 10 of the research studies of the Royal Commission on New Reproductive Technologies (Ottawa: Minister of Supply and Services Canada, 1993).
9. Canadian Fertility and Andrology Society (CFAS), *Guidelines for Therapeutic Donor Insemination* (Montreal: CFAS, 1988), 5.
10. W.J. Millar, S. Wadhera, and C. Nimrod, "Multiple Births: Trends and Patterns in Canada 1974-1990," *Health Reports* 4 (1992): 223-50.
11. Baylis, "Assisted Reproductive Technologies."
12. The terms of reference for the Reproductive Advisory Committee at the Foothills Hospital in Calgary, Alberta, are the following:

Many of the facets of reproductive health care involve social issues which are beyond the comprehension of traditional medical therapy. In an effort to maintain dialogue between society in general and busy practitioners in particular, an attempt is being undertaken by the Department of Obstetrics and Gynaecology to foster a process of active discussion.

1. Structure

The committee will be departmentally structured and will serve the needs of all divisions of the Department of Obstetrics and Gynaecology (i.e., obstetrical and gynaecological). The committee will be chaired by the department head of Obstetrics and Gynaecology and representatives of the Department will include the division heads and one member at large. In addition to membership from the Department, participation will be sought from the hospital administration, a lawyer, an ethicist, a member of the nursing staff, and a member of the lay public.

The meetings will occur quarterly or as deemed necessary by circumstance.

2. Function

The function of this committee is to provide an open vehicle for advice to the various physicians responsible for departmental activities related to clinical management of obstetrics and gynaecology. Although this committee would not be considered policy setting, it nevertheless would be considered to have substantial input in regard to the adoption of critical care decisions.

3. Process

The identification of clinically important areas of concern either by specific patient incident or specific topic will be brought to the Department's attention through this advisory committee. Any member may bring this to the attention of the department head who will call a meeting accordingly.

13. R.S. Thrush and R.R. Lanese, "The Use of Printed Material in Diabetes Education," *Diabetes* 11 (1962): 132-37.

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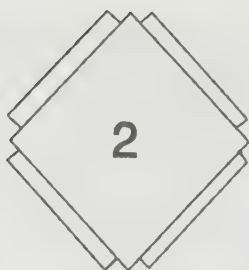
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An Evaluation of Canadian Fertility Clinics: The Patient's Perspective

SPR Associates Inc.



Executive Summary

This report describes the findings of a survey of 1 395 patients of 21 fertility clinics across Canada in 1991. It was designed to gauge the "experiences and feelings ... of fertility clinic patients, and their evaluations of the services they received."

Patients were classified hierarchically, into four groups: *in vitro* fertilization, artificial insemination by donor, artificial insemination by husband, and "other treatments," which consisted mostly of those receiving fertility drugs and those undergoing surgery. After describing and analyzing the demographic profile and treatment histories of fertility clinic patients and their spouses/partners, the report focusses on the diagnoses and treatment they had received/were receiving in the current clinic. Issues such as the direct and indirect costs to patients, how much time elapsed between receiving a diagnosis and being treated, and how long patients were in treatment are examined, as well as the type, quantity, and quality of information, services, and counselling provided by the clinics, how satisfied patients were with them, and how far they met their needs. Patients' and their spouses'/partners' roles in the decision-making process are analyzed, as are the psychological and physical impacts of treatment.

The demographic portrait of fertility clinic patients includes educational and income factors which may affect the accessibility of fertility treatments. The report describes respondents' investment of time, the physical, psychological, and financial hardships they experience, and how these vary according to the treatment. A follow-up substudy of non-respondents to the survey suggests that the results from survey respondents are representative of the broader population of fertility clinic patients. The study points to a number of important conclusions regarding fertility clinics, the treatment process, and patients, including the following:

- The fertility treatment process is complex and involves many steps for patients. Patients received a wide range of consultations and treatments with some patient treatment histories spanning many years. This suggests that patients are deeply committed to finding solutions to their fertility problems.

Patients were often unable to obtain a speedy assessment or diagnosis of their fertility problem and went from one physician or specialist to another before obtaining a diagnosis. These delays defer couples' clear understanding of their fertility problem while they continue to grow older and miss important options in fertility treatments and adoption.

Women with less education and lower incomes take longer, on average, to identify their fertility problems than do women with more education and higher incomes. This suggests that women with fewer resources may be less effective consumers, or may obtain less satisfactory service from the health care system in dealing with their fertility problems. It also points toward important issues in access to fertility treatment, which hinge not on the cost of treatments per se, but, rather, on the effectiveness of the health care system.

- People seeking treatment at fertility clinics are motivated by many factors, but the most important is the patient's personal desire for children. Other motives such as the desire of spouse/partner for children were of secondary importance and pressure from family and friends was of little importance.
- Patients' expectations of having a baby were generally substantially higher than the estimates provided to them by the clinics. This finding, as well as the fact that patients want to know their probability of success, points to the need for more explicit, formal systems for informing patients.
- Higher level reproductive technologies were usually used in the appropriate circumstances (e.g., *in vitro* fertilization for tubal problems), but not in all cases. From the patient's perspective, clinics appear to use these technologies in a wide variety of cases, sometimes when a less invasive technology might be a more appropriate first step in treatment.

- The costs of fertility treatments were high, particularly for *in vitro* fertilization, with patients spending many thousands of dollars directly on clinic costs, drugs, and travel, and indirectly as a result of time lost from work. The total costs for *in vitro* fertilization patients in Ontario were dramatically lower (about \$5 300) than the total costs for *in vitro* fertilization patients from other provinces (about \$9 000).
- Patients' assessments of information provided by clinics varied widely; some topics were reported to be well covered by clinics, but in many areas the information provided by clinics was rated poorly.
- Patients were generally satisfied with the way decisions were made regarding their treatment: most decisions were taken jointly by patients, their spouses/partners, and physicians; only a small proportion of patients reported unilateral decision making by physicians.
- Patients' assessments of the quality of service provided by clinics varied widely. Some clinics were rated as excellent, others as performing poorly. But most patients reported that they would recommend both fertility treatments and their specific clinics to a friend.
- The information and services that were most important to patients were often not those that the clinic provided most effectively. Many clinics provided high quality information, but often it was not the information that patients wanted most. Patients' concerns regarding lack of information are particularly important, since it is difficult to argue that patients have provided informed consent when their valid demands for information are underserved.
- Patients identified a need for more counselling, especially after the conclusion of treatments. By counselling they meant primarily improved consultation with the physician and nurse — counselling by social workers or psychologists was rated as less important to them.
- Clinics generally varied widely in the quality of the service they offered. Many patients reported extraordinarily favourable experiences, while others (a minority) reported very poor treatment both in technical terms and in terms of meeting their needs on aspects such as comfort and dignity.
- Most patients reported that the treatments had a wide range of positive effects, for example, on their self-esteem and their relations with their spouses/partners, but many also reported a wide range of difficulties, such as stress, physical difficulties, and financial problems.
- Patients were generally intent on continuing fertility treatments until they succeeded in having a child or until they could no longer continue financially and emotionally. Many patients pursued adoption while undertaking treatment.

- Public funding in Ontario reduced the cost of fertility treatments for patients but did not result in significantly greater access to treatment by lower income groups.
- Information, counselling, decision making, and informed consent procedures in clinics were important factors predicting patient satisfaction. Those clinics performing well in these areas also performed well on the outcome measure of the success of treatments (measured either as pregnancy or the birth of a baby).

Overall, the survey results suggest that Canadian fertility clinics provide a service that is regarded as extremely important and valuable by their clients. At the same time, the results suggest a need for improved standards, particularly in the areas of information, counselling, and decision making.

Part 1. Introduction

Background

This report evaluates Canadian fertility clinics from the perspective of 1 395 of their patients who, in 1991, received such medical treatments as *in vitro* fertilization (IVF), artificial insemination (AI), and other techniques generally included in the term “new reproductive technologies (NRTs).” This “Evaluation of Canadian Fertility Clinics: The Patient’s Perspective”, was commissioned in February 1992 to provide the Royal Commission on New Reproductive Technologies with information about the experiences and feelings of those most directly affected by these new technologies — current and past fertility clinic patients — and their evaluations of the fertility clinic services they received.

This confidential survey was coordinated with the “Survey of Canadian Fertility Programs” and with other research projects undertaken by the Commission. The Survey of Canadian Fertility Programs and this report — the companion “Evaluation of Canadian Fertility Clinics: The Patient’s Perspective” — were designed to focus on the fertility clinics which provided, and the patient population that received, the more advanced fertility treatments in Canada. The studies focussed on clinic operations in 1991, and clients who were patients of these clinics during 1991. They are best understood if read together.

The evaluation focusses on such issues as the information given to patients, consent procedures, decision making, the psychosocial impact of treatment, and other aspects of treatment. It is based on detailed questionnaire assessments completed by approximately 1 400 patients of Canadian fertility clinics in 1991. Since the clinics in the study offer most of the IVF treatments provided in Canada, the study is relatively comprehensive for that technology. The study also includes patients who received a variety of treatments that are not exclusive to fertility clinics, for

example, those that may be offered in physicians' offices such as AI or fertility drugs; thus the conclusions that are based on the responses of clinic patients may not necessarily apply to patients receiving such treatments in office settings.

The discussions and controversies over NRTs span a wide range of issues, including ethical considerations, the impact of NRTs on women's control of their bodies and reproductive decisions, and the long-term effects of NRTs (impacts of drugs, multiple pregnancies/births, etc.) on women and babies. This study provides information relevant to a specific aspect of the NRT debate — the functioning of fertility clinics, their impact on patients, and patients' satisfaction with them.

A number of key questions were at the forefront in planning the patient survey. They include:

- Who uses Canadian fertility clinics?
- What are the motives and concerns of fertility clinic patients?
- How do fertility clinic patients evaluate adoption as an alternative option?
- To what degree are high-technology treatments such as IVF applied inappropriately?
- To what extent are patients able to control reproductive decisions in the course of treatment?
- Are patients satisfied with the information and the quality of service provided by clinics?
- What is the impact of treatment on patients' feelings of their self-worth?
- What physical and emotional stresses does treatment cause?
- Do patients in different regions of the country generally have access to services of similar quality?
- Do clinics generally provide services of comparable quality?
- Are information, consent procedures, and counselling important contributors to patients' satisfaction and the success of treatment?

While few of these questions could be answered on the basis of previous research, prior work did provide some hypotheses and insights, as we note throughout the report. First, however, we will consider some conceptual issues, and a model of infertility, fertility treatment, and impacts, which provides context for the analysis.

Although definitions of infertility vary, one that is widely used is that "conception has not occurred after one year of a couple having regular intercourse and using no contraception."¹ Infertility has many causes and results in a variety of human and social costs, many of which we will consider here. For those who are having difficulty achieving a family and

who fear they will be denied this personal fulfilment, infertility is a disease or health problem like other problems, and those individuals are quick to reach out for medical or scientific remedy.

Whether infertility is growing in frequency or is just being recognized more as a problem today is not well documented. Nor is it known how common infertility is in Canada. Some observers, however, write of an "infertility epidemic." Even if the incidence of infertility is not changing, "baby boomers" are now into the late reproductive age group and this may create a medium-term upsurge in demands on the health care system from infertile couples. To the extent that these problems have been hidden away statistically because many women deferred childbearing in the past decade, infertility may be an issue of increasing significance in coming years.

The causes of modern infertility are not well understood, but there are a variety of personal, health, and societal factors. They include diseases such as pelvic inflammatory disease from sexually transmitted infections; environmental factors such as chemicals and toxins that affect the ability of some individuals to reproduce; and delayed childbearing (more women trying to have a family at a time in their reproductive lives when they are less fertile). Relatively little attention has been paid to problems of male factor infertility compared with female problems of infertility, in spite of the fact that male infertility is thought to contribute a major part of the total infertility. Because societal decisions and conditions are thought to result in at least a portion of today's fertility problems, many of those with fertility problems claim the right to a societal remedy through the health care system.

Infertility results in a variety of costs to these individuals and to society as a whole. Some human costs that are significant but difficult to measure include:

- lack of personal fulfilment and diminished quality of life and happiness;
- psychological distress;
- family dysfunction and conflict; and
- social and life-cycle effects (i.e., lack of children in old age).

There are also costs to society of infertility. Some of the most significant are:

- the indirect economic costs when stress and family dysfunction affect individuals' productivity;
- the cost to the social services and health care systems when stress results in illness and/or places demands on social services for individual or family counselling, and when individuals are more dependent in their old age because they do not have children to help care for them; and

- the direct costs of treating infertility, which include the costs of surgery, drugs, consultative services, fertility treatments, and care of premature or low-birthweight babies.

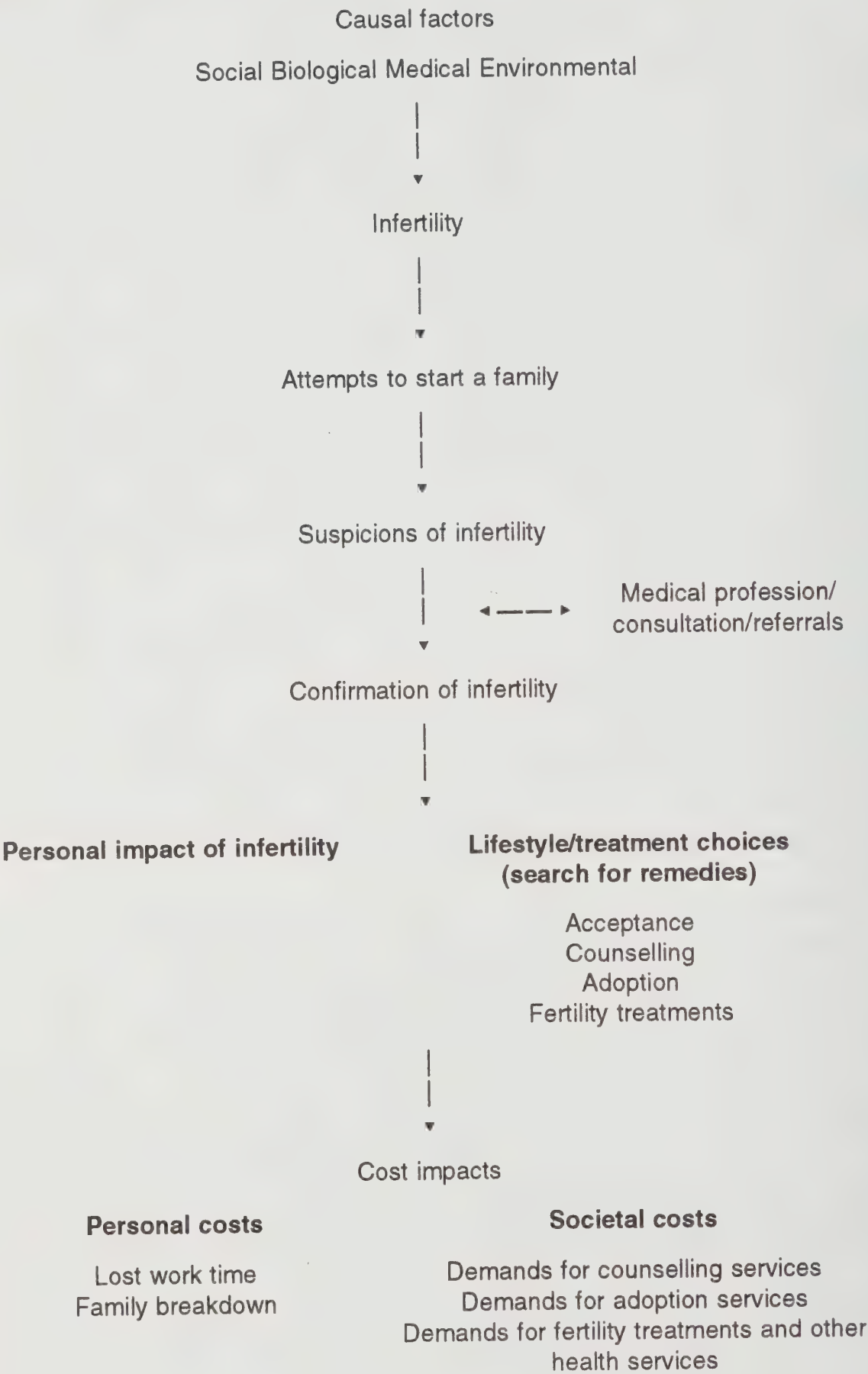
This broader range of the possible costs of infertility provides two useful perspectives on fertility clinics and fertility treatments. First, when the full range of possible impacts and costs of infertility are examined, medical treatment should be considered as only one of the societal methods of dealing with infertility. A full evaluation of the cost-effectiveness of fertility treatments would compare the costs and effectiveness not just of different fertility treatments but also the costs of such services as counselling and adoption as compared to the cost of fertility treatments.

Second, the cost and impact of fertility treatments can be considered in light of the fact that their benefits may go beyond providing babies to the infertile. Such treatments may also reduce stress and improve the quality of individual and family life; improve the quality of life for a couple generally, for example, by improving economic productivity; and reduce demands on other health and social services. Considered in this light, questions arise regarding the extent to which public funding should be provided for specific fertility procedures and the delivery of counselling services with fertility treatments, and regarding what the most appropriate delivery mechanisms are.

From the perspective of the research design, there are several difficulties in evaluating fertility clinics. For example, an experimental study ideally would assign infertile individuals randomly to such solutions as no treatment; counselling to reduce the stress of infertility; adoption; and other fertility treatments at various levels of technical intervention such as drugs, surgery, artificial insemination by husband (AIH), artificial insemination by donor (AID), IVF, gamete intrafallopian transfer (GIFT), and zygote intrafallopian transfer (ZIFT). Such an experiment obviously is not possible.

Patients who start fertility treatment are already suffering from stress resulting from their infertility. Consideration of this prior stress has been problematic for many researchers examining the psychological state of fertility clinic patients. Many of these researchers have studied stress during counselling without drawing a very clear distinction between the psychological stress resulting from the infertility per se, the stress created by the fertility treatments, and the fact that infertility stress may be removed by the fertility treatments.² Since this study is a point-in-time survey it cannot assess the psychological stress resulting from the infertility itself. It does, however, assess the stress directly created and removed by fertility treatments by *asking patients*.

Figure 1.1. Model of Infertility and Fertility Treatment



Fertility Treatments and Their Impact: A Complex Domain

The fertility clinic patients surveyed often brought with them a complex and lengthy history of identifying and dealing with their fertility problems. The variety of consultations and procedures that they undertook and the number of years in active treatment were often remarkable. Patients sought treatments in other countries, in different clinics, and through private practitioners, naturopaths, and acupuncturists.

Every patient history had unique features and its own complexities. Access to fertility clinic treatments is another complex issue. Although this survey does not directly examine access, it does examine related issues such as referrals and time elapsed in identifying fertility problems. It thereby provides important insights into the subject of access and suggests hypotheses for future research.

Fertility treatments are generally carried out within the context of the broader health care system, since most fertility clinics are located in major hospitals. There are, however, two other important ways in which the fertility treatment process is connected to the health care system. First, patients must generally get to fertility clinics by being referred by a family physician, general practitioner, or gynaecologist. How efficiently this system works (or does not work) for those with fertility problems may be suggested by the long time it takes many to discover and determine their fertility problems. Second, the quality of care, information, and service provided by fertility clinics almost certainly reflects the broader standards of the health care institutions in which they are located. Unfortunately, linkage to the larger health care system provides an obstacle to change, since any failings found in fertility clinics might be explained as a function of the broader health care system; that is, change can be resisted on the grounds that "you can't change part of the system, such as fertility clinics, so you have to change the system as a whole."

Previous Research

Patient assessments of medical services have become an important part of research into health services in recent decades as well as an important element in improving the quality and the accountability of health care systems to the public.³ While researchers have conducted a variety of studies of patients of fertility clinics in recent years,⁴ none have provided a national overview of the psychosocial impact of these treatments. Most only partially examine the outlooks of very small samples of patients, and they often fail to distinguish clearly between stress brought to and stress resulting from fertility treatments.⁵

One study that is important for this research is Dr. John Wright's, which focusses on a longitudinal study of several hundred patients at one Quebec fertility clinic.⁶ It suggests that patients suffer a significant amount of stress from treatments, and that there is a substantial need for patients to have more information. For example, the lack of dialogue between the

patient and the doctor and the lack of information are both cited as significant factors in patients withdrawing from treatment. The study results also suggest that there is a need for more support and counselling from family physicians and general practitioners (not necessarily psychological counselling). These results are also reflected in a number of smaller studies reviewed by Muir.

The Scope of this Study

This evaluation of Canadian fertility clinics from the patient's perspective should be considered in light of complexities, constraints, and issues such as the nature of the evaluation, and its target audience; difficulties with evaluative criteria; the heterogeneity of Canadian fertility clinics; and the complexity of the fertility treatment process.

This study has been conceptualized as a consumer evaluation of fertility treatment services. It differs in one important respect from most evaluations that suggest corrective action if and as needed. No single organization or body can act on all of the findings of this study because no single agency has a mandate to regulate or manage fertility clinic services in Canada. As a result, the report will be primarily of informational value to a wide variety of parties, including:

- the Royal Commission on New Reproductive Technologies, which will make recommendations to the federal government;
- provincial governments, which can regulate fertility clinics within the health care system and can fund or not fund specific treatments;
- professionals delivering services in fertility clinics;
- institutions that operate fertility clinics (hospitals, universities, and corporations);
- patients or prospective patients of fertility clinics; and
- the general public.

Evaluating fertility clinic services is made difficult by the lack of standards or guidelines in a number of key areas, such as in the provision of information and counselling, or in procedures for obtaining informed consent. This lack of standards may result in some ambiguity in determining the significance of findings. For example, if only half the clinics require a certain type of written consent, is it a positive feature that half the clinics do so and is it a problem that half do not?

As well, the use of the findings from our evaluation for policy purposes may be confounded by the lack of a clear model that explains how exactly quality care can be maximized. Many areas of universal concern that might be examined here (for example, record keeping) would reflect broad practices in the health care system generally rather than specific practices in fertility clinics as a unique class of health services. To take the example

of record keeping, if a hospital-based fertility clinic is assessed as having poor record keeping, this might reflect the general record keeping in the hospital in which it is located. As already noted, most aspects of patient care — information, consent procedures, decision making — reflect the broader institutional health care system and all of its features, including resource scarcity.

The Context of the Study

Fertility clinics provide a service that responds to deep human concerns related to procreation. Other important linkages can also be found with issues of human rights, women's equality (control over reproductive decisions), and even economics (in traditional societies, for example, having children has always been motivated by more than just biology — it is, in fact, a part of economic planning in which children constitute both a supply of labour and "social security"). The depth of these human concerns is shown in this study by the intensity and passion of those seeking fertility treatments — for many, no sacrifice or pain is too great to achieve their goal of having a baby.⁷ These individuals are not unique in this desire. Having a family is a very important part of most people's lives in Canada.⁸

Fertility treatment is a complex process in more than just clinical terms — couples seeking fertility treatments will often spend years and tens of thousands of dollars (in direct costs and lost income) in their efforts to have a baby, with no assurance of success. The complexity of this process raises particular challenges for a study designed to capture data through a survey, as surveys must simplify matters to allow presentation of clear questions.⁹

Heterogeneity of the Fertility Clinics

Canada's fertility clinics vary considerably in important ways. Some are located within major teaching hospitals, others are located in other types of hospitals, and a few are operated privately. They also vary considerably in how they deal with patients and in the range of services they provide. These variations are particularly substantial in the areas of information and informed consent.

Fertility as a Women's Issue

While fertility concerns all of us and concerns both women and men in a given family or relationship, there are particular reasons why women are at the forefront in all fertility treatments. Foremost of these is that women must bear the brunt of most medical treatments — they generally are the recipients of most of the drugs and most of the surgery. As well, as many of those surveyed pointed out, male infertility seems to be the subject of far too little attention in this field. Should fertility treatment be seen primarily as a women's issue? Or is it important that fertility treatment be seen as a 'couples' issue? Does it have to be viewed as either? Why not both? In this study, most clinics identified their patients as females (they

were the ones to whom clinics addressed the survey), even where the problem was male pattern infertility and even though most clinics indicated that “the couple” was the “unit” of treatment.¹⁰ Even when the survey was addressed to couples, women almost always identified themselves as “the patient.”

An Overview of Infertility and Canadian Fertility Clinics

Historical Background¹¹

Treatment of human infertility has a long history that goes back to the first recorded successful AI of a human being in the eighteenth century. Only in the last half of this century, however, has the apparent need for and capability of intervention resulted in AI being provided by many medical practitioners on a large scale. And only in the past few decades has this been extended to AID and innovative technological applications such as IVF.

Since 1978 when the first “test tube” (IVF) baby was born in England, there has been a great deal of interest in new reproductive technologies among both the medical establishment and the Canadian public at large. In 1982 the first Canadian IVF babies — twin boys conceived in a clinic in England — were born in Oakville, Ontario. The first IVF clinics in this country were established in a low-key manner. No funding was provided to the first two clinics to establish practices — one at le Centre hospitalier de l’Université Laval in Quebec City (1980) and another at the University of British Columbia (1982). At least a dozen more clinics opened in Canada over the following years, and a key event in Canadian IVF history was the decision in 1985 by the Ontario government to fund the procedure through the Ontario Health Insurance Program (OHIP). The emergence of these treatments and the expansion in the delivery of treatments may have been accelerated by what some observers have suggested is a growing problem of infertility in the twentieth century. Whether, in fact, infertility is more frequent now than in the past is not known.

Fertility Clinics in Canada Today¹²

Until the Survey of Canadian Fertility Programs in 1992 there was no definitive list of Canadian fertility programs. Using that survey it is now possible to classify Canadian fertility programs according to their location (in hospitals and private clinics)¹³ and as to some other characteristics. There are 41 fertility programs¹⁴ in 27 locations (hospitals/clinics) in Canada (see Table 1.1). There are 17 IVF/GIFT/ZIFT programs in Canada, 11 in teaching hospitals and 6 in other hospitals and private clinics; there are 24 AI programs (the term AI is used in the generic sense to refer to both AIH and AID) of which 19 are in teaching hospitals and 5 are in other hospitals and private clinics.

Table 1.1 Classification of the Universe of Canadian Fertility Programs According to Activity and Setting in 1991

	Total	IVF, GIFT,* ZIFT**		AIH, TDI,*** IUI****	
	All settings	Teaching hospitals	Other hospitals and clinics	Teaching hospitals	Other hospitals and clinics
All programs (27 sites)	41	11	6	19	5
Grace Hospital, Halifax	2	●		●	
Centre hosp. univ. Laval, Quebec	2	●		●	
Hôpital St-Sacrement, Quebec	1			●	
St-François d'Assise, Quebec	1			●	
Hôpital de Chicoutimi	2	●		●	
Centre hosp. univ. Sherbrooke	1			●	
Hôpital St-Luc, Montreal	2	●		●	
Montreal General Hospital	1	●			
Royal Victoria Hospital, Montreal	1			●	
Hôpital Sacré-Coeur, Montreal	1			●	
Inst. Med. Reproduction Montreal	2		●		●
Ottawa Civic Hospital	2	●		●	
Ottawa General Hospital	1			●	
Toronto Hospital, General Division	2	●		●	

Table 1.1 (cont'd)

	Total	IVF, GIFT,* ZIFT**		AIH, TDI,*** IUI****	
	All settings	Teaching hospitals	Other hospitals and clinics	Teaching hospitals	Other hospitals and clinics
St. Michael's Hospital, Toronto	1			●	
Toronto Fertility Sterility Institute	2		●		●
C.A.R.E. Centre, Mississauga	2		●		●
LIFE, Toronto East General Hosp.	2		●		●
IVF Canada, Scarborough	1		●		
Markham-Stouffville Hospital	2		●		●
Chedoke-McMaster Hospital, Hamilton	2	●		●	
University Hospital, London	2	●		●	
Health Sciences Centre, Winnipeg	1			●	
Royal University Hospital, Saskatoon	1			●	
Foothills Hospital, Calgary	2	●		●	
Health Sciences Centre, Edmonton	1			●	
University Hospital, Vancouver	1	●			

* Gamete intrafallopian transfer
** Zygote intrafallopian transfer
*** Therapeutic donor insemination
**** Intrauterine insemination

Figure 1.2 Regional Distribution of Fertility Clinics, 1991



In most of the teaching hospitals both IVF and AI are offered, usually at the same site. However, in some cases the IVF and AI programs are administered autonomously and have different staffs, different locations within a single institution, and different administrative criteria. The IVF and AI programs at private clinics and non-teaching hospitals were found to be relatively integrated when compared with those in the teaching hospitals.

Fertility clinic programs are highly clustered in Ontario and Quebec; for example, one-third of all fertility clinics are in southern Ontario (see Figure 1.2) — and correspondingly, the number of patients is also very high. This may be accounted for in great part by Ontario's policy of funding IVF under OHIP. Outside Quebec and Ontario there are six fertility clinics providing AI and "other treatments," but only three offer IVF.

The fertility clinic programs vary widely in size; in 1991 the number of patients in the various IVF programs ranged from 12 in the smallest program to 515 in the largest program. In that year, it was estimated that there were a total of approximately 2 900 patients in IVF programs and another 3 400 in AI treatments (it should be noted that fertility clinics may have other types of patients as well, for example, those receiving fertility drugs, other treatments, or surgery). As noted, the number of patients is difficult to quantify precisely because of the ways clinics keep patient records, often tabulating visits or cycles rather than numbers of patients. Clinics also vary greatly in style — how patient-centred their approach is and their use of counselling. For example, some clinics have their own professional counselling staff, some use the counselling services of the hospital in which the clinic is located, some make referrals, and others do none of these.

Study Methodology and Limitations

The survey was designed in the first few months of 1992 by the SPR Associates research team working with the Commission staff and a team of medical research advisors. Reference was made to a wide range of previous studies and surveys to conceptualize and develop measures.¹⁵ The design phase resulted in a well-defined survey procedure and a highly refined, if somewhat long, questionnaire (11 pages of questions, and a 12-page booklet — see Appendix 1 for English and French versions of the questionnaire). Letters were sent out to fertility clinic directors asking them to participate in the survey. These letters were accompanied by a sample questionnaire and background material. Subsequently, the research team provided additional information and responded, as needed, to particular requests for review by ethics or research committees. Overall, clinic participation and cooperation was extremely good. Twenty-one of the 27 fertility clinics in Canada, approximately 80% of fertility clinic programs, and a somewhat greater proportion of patients agreed to participate in the study (see Appendix 2 for details regarding the six non-participating

clinics). In every case where the survey procedure was subjected to a formal review by a university ethics committee, approval was received.

Sampling and Operations

The sampling frame for the survey was all patients of Canadian fertility clinics receiving treatment in 1991. Sampling of this population was complicated by (1) the inability to access patient records directly for reasons of confidentiality; and (2) the absence, in most clinics, of easily accessible lists or data bases that could be used for sampling design. Indeed, at the start of this survey, there was considerable uncertainty in most fertility clinics regarding the actual number of patients receiving the various treatments, as many clinics kept aggregate statistics by the number of cycles or treatments, not the number of patients. Thus, the researchers had to consult with clinic staff to estimate numbers of patients prior to the actual sampling.

The research team took several steps to maximize the success of this survey within the Commission's time frame. The most important step was to have a substantial number of initial mailings — namely 3 450. In sampling the individual clinics, the study team's strategy placed considerable emphasis on factors of cost, representation of key clinic types, and geographic regions. One hundred percent sampling was undertaken for most clinics surveyed, with fractional sampling used only for the clinics with the very largest patient populations. More than 40% or about 1 400 of the surveys distributed were completed and returned by patients, a very good response for a single mailing. It suggests minimal non-response bias, an assessment that was validated by a substudy of non-respondents (see below). The surveys were returned directly to the researchers (i.e., not via the clinic) and respondents were informed that their answers *would not* be made available to their clinic.

Survey Response Patterns

Several steps were taken to determine whether the respondents were representative of the patient population as a whole. Most importantly, the non-respondents from two clinics were studied to see how they differed from respondents. Overall, no statistically significant or substantial differences were found between non-respondents and respondents. Non-response bias was, therefore, not considered to affect the validity and generalizability of the survey results (these issues are discussed in Appendix 2).

There is considerable evidence that the survey was well received among the patients and that many were glad of the opportunity to have input. In some clinics, patients for the year 1992 who learned of the survey asked if they could also participate (they were not included in the survey). In several specific cases, a patient involved with more than one clinic completed a questionnaire for each clinic, a number of patients who misplaced their questionnaires telephoned asking for another, and many patients telephoned the survey office to ask for a questionnaire in the

appropriate language (where the original questionnaire was not in the patient's language of choice). Generally, the returned surveys were very thoroughly completed and provide a wealth of commentary.

Statistical weights were applied in estimating tables for the report to assure the representativeness of the survey estimates (see Appendix 2), and statistical data processing was conducted using SPSS (Statistical Package for the Social Sciences).

Data Quality and Reliability

To test the statistical reliability of key attitudinal indicators used on topics of information, decision making, satisfaction, and the psychosocial impact of treatment, a variety of statistical tests were conducted. These included factor analysis and estimation of alpha reliabilities for each of these key indicators.¹⁶ Overall, this analysis indicated very high reliabilities for all scales tested, suggesting good reliability of the data examined throughout the report. All scales were estimated to have alpha reliabilities in excess of 0.7 (Table 1.2).

Table 1.2 Reliabilities of Selected Indicators*

Alpha	Indicator
0.88	Total amount of information received (Section D.1)
0.93	Patient satisfaction with clinic information (Section D.1)
0.92	Patient priorities placed on information (Section D.2)
0.90	Patient satisfaction with clinic services (Sections D.3 and D.5)
0.81	Match of clinic information/services to patient's needs (Sections D.1 to D.6)
0.89	Positive impacts on patient (Section E.1)
0.76	Difficulties for patient (Section E.2)
0.86	Positive impacts on spouse (Section F.1)
0.78	Difficulties for spouse (Section F.2)
0.79	Number of consent procedures followed (Section B.10)

* Indicators were created by combining appropriate questions within the sections indicated. Numbers of sub-items varied from as few as 7 items to over 20 items per indicator.

Limitations of the Study

Although the survey on which this evaluation is based provides extensive data of good reliability on a number of key issues, including patient information, informed consent, decision making and psychosocial impacts, the study methodology and data reliability are limited in several

ways. The study directly examines in detail only part of the fertility clinic process — the experiences of patients who actually undertook treatment and particular aspects of information received (decision making and the psychosocial impact of treatment). Data on these aspects are reliable, as we have noted. However, the data do not address in detail the issues of access to treatment or those relating to the long-term psychosocial or clinical effects of treatment. The survey provides only a snapshot view of the clinical and technical details of treatment, as viewed by patients. Since these may not always be complete or accurate regarding technical issues (e.g., diagnoses and exactly what treatments are provided), the researchers deliberately restricted questioning on treatment to broad issues such as the types of treatment received and the length of time in treatment.

Some of the issues are also complex and difficult to measure. For example, informed consent implies that a high level of information has been provided to the patient about the risks of treatment. It is difficult, however, to measure this directly. In this instance, an approximation was obtained in the survey, with independent measures of the amount of information the clinic provides, the match of information to the patient's needs, and the extent of the formal (written) consent procedures.

Measurement issues are also complicated by the one-time and — for those patients who have ended their treatment — after-the-fact nature of the survey. For example, patients' recall of the key events prior to or during treatment may not be accurate in every detail, especially when the process has unfolded over several years. Similarly, a patient's recall of some features may be modified by subsequent events, even over a short period of, say, one year or less. For example, a study over time might illustrate that the evaluations of patients who eventually succeeded in their fertility treatments may tend to be more positive than those of patients whose outcomes were less successful.

It is also difficult to compare some key treatment subgroups, an issue of substantial methodological complexity because of the cross-sectional or one-point-in-time nature of the survey. For example, it would be easy to consider patients who have concluded treatment as typical of all of those who have completed the treatment process. But in a point-in-time survey (compared with a study of a single cohort, for example, a group of patients who all began treatment in the same year), this group will under-represent those who have stayed in treatment longer and over-represent patients who withdrew from treatment because of dissatisfaction.

Using a single (self-completed) survey did not allow in-depth treatment of every issue. For example, we asked patients about counselling they received and the extent to which it was satisfactory, but the limited questionnaire length in the main survey did not allow the researchers to determine all details as to who gave the counselling and what the counselling was about. (This particular issue was, however, examined in a supplementary survey that asked respondents who they received counselling from, if they wanted more counselling, and who they wanted to

receive the counselling from.) Thus, on some issues the study may be of greater value in identifying questions for future research.

Data Drawn from the Survey of Clinics

The design of the patient survey was strongly influenced by the previously initiated Survey of Canadian Fertility Programs, which provided the initial listing of clinic programs and the initial estimates of the number of patients served by each fertility clinic in 1991.¹⁷ Several indicators from that study were used in our survey, including public/private and teaching/non-teaching hospital status, indicators of the presence of counselling resources and referrals for counselling, indicators of the presence of patient support groups, and indicators of the quality and readability of printed information for patients.¹⁸ These data were linked directly to the patient survey data base, so that correlations could be drawn between such characteristics as the teaching hospital status of a clinic and patient satisfaction with services (see Part 9).

Classification of Patients

Patients were classified into four groups according to the treatment they received, as follows:¹⁹

- those patients indicating that they received IVF treatment at any time at the clinic were assigned to the IVF group, regardless of other treatments received. A small number of patients receiving ZIFT and GIFT were also included in this group;
- among the remaining patients, all those who received AID were assigned to the AID group, regardless of whether or not AIH or other treatments were also received at the clinic;
- among the remaining cases, all AIH recipients were assigned to the AIH category; and
- all other patients who had not received either IVF, AID, or AIH were assigned to the "other treatments" group (this group consisted mainly of patients who received fertility drugs; another large subgroup included those who were treated surgically).

These four treatment groups are used throughout the report in the statistical tables. The rationale for this relatively simple classification was (1) to provide a simple scheme for comparisons; and (2) to separate patients who had received the most demanding treatment (IVF) and those receiving AID (again, a more sensitive treatment) from those receiving AIH and "other treatments." The reader should be aware that some patients — perhaps 10% — received more than one of the major treatments examined. This classification method assigned multiple-treatment cases hierarchically, first to IVF (where that treatment was received), second to AID, and third to AIH.

The final study data base included 1 395 completed patient questionnaires, with the following breakdown within the above classification: IVF (773 patients), AIH (146 patients), AID (159 patients),

and “other treatments” (317 patients). Overall, these samples are substantial enough to allow good confidence in statistical estimates, particularly as regards the IVF group.

Some issues called for more detailed statistical analysis (see Appendix 3). For these, a number of additional statistical breakdowns are provided that include some statistics on those who successfully ended their treatment compared with those who regarded their treatment as ended and unsuccessful. The mean values for key variables by treatment type are also provided in Appendix 3.

Part 2. Fertility Clinic Patients and their Spouses/Partners

Social-Demographic Characteristics of Patients

To describe the population of fertility clinic patients and to assess aspects of access, we examined fertility patients and their spouses/partners in terms of age, sex, language, education, and employment (see Table 2.1). Fertility clinic patients were predominantly between the ages of 30 to 39 years. Only a small number of IVF patients were aged between 20 to 30 and over 40 years, whereas one-third of all non-IVF patients were found in these age groups. This tendency for the patient group to be relatively older in their childbearing years may reflect a variety of time dynamics in fertility treatments. As we will see below, on average it takes several years to move from being concerned about infertility to identifying the problem and to getting treatment at a fertility clinic. This pattern was reflected particularly by the age distribution of IVF patients who were substantially older as a group than those receiving other treatments.

More than 99% of patients were female. This selection relied on who was identified as “the patient” by the clinic, and the fact that on the completed surveys, the female was generally identified as the patient, even when the treatment was donor insemination. (It should be noted, however, that even though the patients were generally females, most clinics indicated on the parallel survey of fertility programs that they treat couples rather than individual patients.)

The majority of patients (about three in four) reported their first language to be English. A substantial minority (about one in six) reported French to be their first language, and a small minority (about one in 10) reported their first language to be other than English or French. This pattern of English as a first language was strong for IVF patients, who were much more likely to report English as their first language than either AI patients or patients in “other treatments” groups. This reflects the geographic distribution of the IVF clinics, particularly the high concentration in Ontario.

Table 2.1 Demographic Characteristics of Fertility Clinic Patients, by Treatment Type (%)*

	Treatment Type			
	IVF	AIH	AID	Other treatments
Age				
Under 30	12	29	28	32
30 to 39	80	63	65	65
Over 40	7	8	7	3
Sex				
Female	100	100	100	98
Male	0	0	0	2
Language				
English	78	67	72	69
French	10	21	20	23
Other	11	12	8	8
Education				
Up to grade 11	7	3	4	9
High-school graduate	21	33	23	20
Community college/ technical school	28	33	27	28
University	36	24	36	35
Postgraduate studies	8	6	9	8
Employment in 1990				
Employed full-time all year	66	60	63	58
Employed full-time 30 weeks or more	8	7	9	11
Other, employed part-time or part year full-time	4	5	6	8
Not employed at all	22	27	22	23
Employment in 1991				
Employed full-time all year	59	55	57	52
Employed full-time 30 weeks or more	8	8	4	15
Other, employed part-time or part of year full-time	7	7	8	9
Not employed at all	26	30	30	24

* Figures may not add to 100% due to rounding.

Patients appeared to have relatively high levels of education; a substantial portion (about four in 10) reported having a college or university education.

They reported moderately high labour force activity in 1990 and 1991, with the majority of patients (about six in 10) indicating full-time employment and a smaller number (about one in 10) indicating part-time or part-year employment. About one in four indicated that they were not employed at all in the time period examined. It was not possible to estimate the exact extent to which labour force participation is affected by having fertility treatments.

It should be noted that in the general population the prevalence of infertility is higher among couples with lower levels of education²⁰ and those in non-professional occupations. Thus, higher levels of education, employment, and salary of respondents indicate better access to fertility clinics by higher socioeconomic groups (although more equal use may prevail when hospitalization is needed).²¹ As we will note in Part 3, both education and mother tongue appear to affect how quickly patients are able to progress from suspecting a fertility problem to diagnosing it.

Social-Demographic Characteristics of Spouses/Partners

The demographics of spouses/partners closely mirrored those of patients (see Table 2.2). Like patients, spouses/partners were predominantly aged 30 to 39 years, but a larger subgroup was over 40 years and a small percentage fell into the under 30 group. The average age of female spouses was 34 years, and of male spouses 38 years, reflecting the situation in the general population where husbands are usually somewhat older than their wives. As with patients, the majority of spouses/partners reported their first language to be English, with slightly more spouses/partners than patients indicating French or another language to be their first language. A high level of education was also indicated for spouses/partners, but, interestingly, they seem to have a slightly lower level of education overall than was reported for patients. Nearly all spouses/partners reported that they were employed in 1990 and 1991, mostly full-time, reflecting the high national average labour force participation for adult males younger than 65 years.

Table 2.2 Demographic Characteristics of Spouses/Partners* of Fertility Clinic Patients, by Treatment Type (%)**

	Treatment type			
	IVF	AIH	AID	Other treatments
Age				
under 30	8	9	12	16
30 to 39	72	73	66	79
over 40	20	18	22	5
Sex				
Female	0	0	0	2
Male	100	100	100	98
Language				
English	76	60	63	69
French	9	20	23	23
Other	15	20	14	8
Education				
Up to grade 11	9	9	15	12
High-school graduate	20	23	20	21
Community college/ technical school	28	37	29	27
University	31	28	26	31
Postgraduate studies	12	3	10	9
Employment in 1990				
Employed full-time all year	86	86	80	80
Employed full-time 30 weeks or more	7	5	7	9
Other, employed part-time or part year full-time	2	3	6	3
Not employed at all	5	5	7	8
Employment in 1991				
Employed full-time all year	84	82	74	79
Employed full-time 30 weeks or more	6	8	5	8
Other, employed part-time or part of year full-time	4	2	14	6
Not employed at all	5	8	7	7

* Seventy percent of spouses/partners completed their sections of the survey, though patients provided all or part of the spouse information in about 15% of cases.

** Figures may not add to 100% due to rounding.

Family Income

Patients of fertility clinics tended to report fairly high incomes (see Table 2.3), which possibly reflects a selection process as a result of the expense of all fertility treatments, but particularly for IVF (see Part 4 for a discussion of costs). While the majority of patients in all treatment groups reported family incomes in excess of \$50 000 per year, less than 10% reported family incomes of under \$30 000 per year.²² IVF patients reported relatively high family incomes: about 8 in 10 reported incomes over \$50 000, with only about 1 in 20 reporting family incomes under \$30 000. In contrast, AI and “other treatment” patients reported somewhat lower incomes than the other treatment groups — about 6 in 10 reported incomes over \$50 000.

Table 2.3 Family Incomes of Fertility Clinic Patients, by Treatment Type (%)*

	Treatment Type			
	IVF	AIH	AID	Other treatments
Total annual family income				
Under \$20 000	1	1	6	4
\$20 000 - \$29 999	4	7	5	11
\$30 000 - \$39 999	7	14	17	16
\$40 000 - \$49 999	11	11	15	16
\$50 000 - \$59 999	15	17	16	11
Over \$60 000	62	50	41	43

* Figures may not add to 100% due to rounding.

These relatively high incomes may reflect factors other than the costs of fertility treatments in screening out low-income potential patients. For example, they may reflect higher labour force participation among the women in these families compared with most women in their age group, as child-rearing will have drawn only a very small proportion of the women participating in the study from the labour force. Study participants are therefore more likely to be working outside the home than other women in the same age group who have children. As well, income, like education and mother tongue, appears to affect the speed with which couples are able to obtain verification and diagnosis of their infertility (see Part 3).

Existing Children and Adoption

The great majority of the couples — four out of five — had no children and wanted to fulfil a primary goal of having children. However, about one

in five of couples had a child or children at the time the fertility problem was identified. Almost none of these children had been adopted, and most were under the age of 16 and still living at home. These cases included couples wanting another child, patients or spouses/partners having a child by a previous marriage/relationship but now identifying a fertility problem in having a child within their current marriage/relationship, and those wanting to reverse a tubal ligation or vasectomy. These results are consistent with Williams' observations that many IVF patients had complex strategies. For example, some were endeavouring to have another child by IVF even while they were in the process of adopting.²³

Most patients reported that at the time they began fertility treatments, adoption was not an option because of age or health, or because they had not considered it as an option, or because they had not acted on it (Table 2.4). Approximately 1 in 10 of patients in the AIH, AID, and "other treatments" groups had applied for adoption. Of the IVF patients, most had considered adoption as an alternative, and about one in five had actually applied for adoption. The proportion of patients considering or actually applying for adoption rises noticeably between the start and the conclusion of treatment. Apparently, after spending several years trying to become pregnant, patients who are unsuccessful are more likely to consider adoption.

Table 2.4 Presence of Children and Adoption-Related Activities, by Treatment Type (%)

	Treatment type			
	IVF	AIH	AID	Other treatments
Presence of children				
Had children already when infertility discovered	19	26	23	23
Parentage of children*				
Children born to patient and spouse/partner	26	65	9	52
Patient's children from a previous relationship	37	11	30	17
Partner's children from a previous relationship	37	35	56	26
Children you and spouse adopted	0	0	0	0
Adoption-related activities				
<i>Whether considered adoption after fertility problem was discovered but before clinic treatments</i>				
Yes, applied for adoption and adopted	3	0	1	2
Yes, applied for adoption but not approved	0	2	1	0
Yes, applied for adoption and still waiting	17	7	10	7

Table 2.4 (cont'd)

	Treatment type			
	IVF	AIH	AID	Other treatments
Adoption-related activities (cont'd)				
Other, applied for adoption (e.g., then cancelled)	3	3	2	2
Yes, considered adoption but did not apply	30	25	37	32
No, did not consider adoption at all	47	63	49	57

* Percentages based on subsample of patients with children at time infertility discovered. For example, among the 19% of IVF patients with children at the time infertility was discovered, 26% of patients had one or more children born to them and their current partner. Multiple responses were possible. (For AID and "other treatments" group, percentages may not add to 100% due to missing data.)

Part 3. Patients' Fertility Treatment Histories

Discovering Infertility and Previous Consultations

Patients reported a wide variety of experiences in terms of time elapsed in discovering their fertility problem. Among these, a small proportion (about 3%) "always knew" about their fertility problem (from earlier medical assessments). Generally, however, they reported a substantial amount of time elapsing between suspecting and confirming their infertility.

Most patients became aware of their infertility within three years of beginning to try to have a child, but a noteworthy minority — about 1 in 10 — spent up to seven years or even longer trying to have a child before suspecting or facing suspicion of a fertility problem (Table 3.1A). Many had been living with their spouses/partners for between three to seven years or longer, before confirming their fertility problem. These results seem to suggest that many people defer having children, which means there is a substantial delay in individuals discovering their fertility problem. If fertility is not tested until later, then options close as patients grow older and have less time to try fertility treatments or to wait for adoption.

Patients were likely to have seen a variety of physicians about their fertility problems before first going to the fertility clinic (Table 3.1B). Those having IVF had frequently seen gynaecologists and less frequently family physicians before becoming IVF patients. AI patients were somewhat more likely to have seen a family physician before attending the clinic, and, interestingly, nearly half of all AID patients had been seen by a urologist before attending the clinic.

Table 3.1A Length of Time Patient Spent Trying to Have a Child and Living with Spouse/Partner Before Fertility Problem Was Discovered/Realized, by Treatment Type (%)*

	Treatment type			
	IVF	AIH	AID	Other treatments
Always knew about fertility problem	3	1	7	0
Years trying for a child when discovered infertility				
Up to three	89	86	83	90
Three to seven	7	13	13	10
More than seven	4	1	4	0
Years living with partner before aware of infertility				
Up to three	56	51	57	56
Three to seven	34	43	37	39
More than seven	10	6	7	5

* Figures may not add to 100% due to rounding.

Table 3.1B Previous Visits to Another Clinic, Physician, or Specialist Regarding Fertility Problem,* by Treatment Type (%)

	Treatment type			
	IVF	AIH	AID	Other treatments
Family physician	50	60	50	52
Gynaecologist	73	55	38	50
Fertility specialist	27	14	7	6
Urologist	10	15	45	9
Endocrinologist	4	5	2	2
Other specialist	2	2	0	1
Other fertility clinic	10	6	5	3
Other source	1	4	0	0
No previous consultation	11	13	12	20

* Multiple responses were possible.

About half of the patients sought a diagnosis within 12 months of suspecting a problem, but for many these consultations extended over time — often spanning a period of several years. After first suspecting a fertility problem, close to half of all patients delayed for one to two years before seeking a medical diagnosis. When they sought a diagnosis, many patients “bounced” from one professional to another or from one fertility clinic to another, sometimes for years, before first approaching the particular fertility clinic they attended in 1991.

Considering the importance of an early diagnosis to maximize patients' options, the researchers posed the question of whether any evidence in the data collected by the survey explained why so many patients took many years to realize and confirm their fertility problems. The researchers examined the impact of several demographic factors on the speed with which patients obtained a diagnosis (Table 3.1C). Time elapsed in obtaining a diagnosis was defined as the total of: (1) months trying to have a child after suspecting a fertility problem; and (2) months elapsed between that first suspicion of infertility and obtaining a diagnosis. When time elapsed is analyzed by patient/spouse education, income, and birth language, several relationships are indicated: (1) patients and their spouses with lower educations (high school or less, or community college) were more likely to take longer to obtain a diagnosis (more than 60 months) and less likely to obtain a speedy diagnosis (under 12 months); (2) higher-income patients were more likely to obtain a speedy diagnosis; and (3) those with a birth language other than English or French were more likely to take a somewhat longer time to obtain a diagnosis (this last difference was not statistically significant).

These relationships are indicated by the survey data but not readily explained. One possible explanation may be that patients with higher incomes/education are more likely to be aware of or seek medical assistance for these types of problems. Another possible explanation may be that in the medical screening process (e.g., contact with physicians and others), less comprehensive service is provided to those with lower incomes/education.

These apparent variations in access to fertility treatments may have important implications for the impact of public funding for fertility treatments. If lower-income couples are less able to identify fertility problems or likely to be significantly older when the fertility problem is diagnosed, they will be even less likely to have fertility treatments if these are not publicly funded (see Part 9).

Table 3.1C Demographic Characteristics of Patients and Spouses/Partners by Elapsed Time (Months) Before Obtaining a Diagnosis (%)*

	Months before obtaining a diagnosis			
	0 - 12	12 - 36	36 - 60	60+
Patients' education				
High school or less/community college	54	58	67	81
University	36	34	24	15
Postgraduate studies	10	8	9	4
Spouses'/partners' education				
High school or less/community college	49	55	71	78
University	34	31	17	17
Postgraduate studies	17	14	13	5
Total annual family income				
\$30 000 - \$39 000	15	17	28	34
\$40 000 - \$49 999	12	13	16	15
\$50 000 - \$59 999	14	17	16	11
Over \$60 000	59	52	41	40
Patients' birth language				
English	76	73	66	70
French	16	18	19	17
Not English or French	8	9	15	13

* Figures may not add to 100% due to rounding.

Previous Fertility Treatments

Patients were likely to have received a wide variety of treatments before attending the fertility clinic. This reflects the complicated path followed by many in dealing with their fertility problems and the tenacity with which they follow it (Table 3.2). IVF patients had a large number and range of previous treatments. Over 70% of IVF patients received surgery, almost a quarter were treated by AIH, and over half received fertility-drug therapy before going to the fertility clinic they attended during 1991. Some of the treatments and tests reported by patients include hysterosalpingograms and sperm analysis, treatment for endometriosis, ovulation monitoring, tests of hormones, and IVF at other clinics. A small number had had thyroid medication and “oriental medicine.” There was a relatively high incidence of surgery (especially laparoscopies) across all patient groups, particularly among IVF patients, and there was also a relatively high incidence of fertility-drug therapy, particularly among IVF and AIH patients.

Table 3.2 Treatments Received Before Attending Current Clinic,* by Treatment Type (%)

	Treatment type			
	IVF	AIH	AID	Other treatments
Fertility drug therapy	52	53	21	46
AIH	23	31	6	5
AID	2	0	9	1
Surgery	71	42	35	35
Other treatments	16	20	6	10
No previous treatments	14	24	51	34

* Multiple responses were possible.

Referrals²⁴

Not surprisingly, considering the range of medical contacts and the variety of treatments patients experienced prior to attending the current fertility clinic, gynaecologists and family physicians/general practitioners played a major role in referrals to fertility clinics (Table 3.3). But many other factors were also reported to be significant in referrals, for example:

- gynaecologists played a significantly greater role than family physicians/general practitioners in referrals for IVF patients; twice as many referrals for IVF came from gynaecologists than general practitioners;
- gynaecologists and family physicians/general practitioners played an approximately equivalent role in referrals for AI and "other treatments";
- other fertility specialists played a somewhat lesser but still prominent role (27%) in referrals for IVF patients;
- approximately 1 in five of patients were self-referred in all groups; and
- a wide variety of other people (including spouse, friends, and family) were involved in referrals for all treatment groups.

Table 3.3 Sources of Referral to Clinic,* by Treatment Type (%)

	Treatment type			
	IVF	AIH	AID	Other treatments
Family physician/general practitioner	25	34	34	39
Gynaecologist	52	36	36	46
Self-referred	19	20	19	24
Fertility specialist	27	6	6	5
Spouse/partner	7	7	9	8
Friends	8	18	16	15
Other family member	4	10	4	8
Other specialist	2	3	6	3
Other fertility clinic	4	0	4	0
Other	1	2	0	4

* Multiple responses were possible.

The Role of Information in the Decision to Attend the Clinic

Consistent with the extensive consultations and treatment experiences of patients and reflecting the importance of fertility issues to individuals, information gathering was a major factor in patients' decisions to seek treatment from the fertility clinic (Table 3.4). Gynaecologists and family physicians played a large role in providing information to patients, with gynaecologists playing a large role in particular to IVF patients. Information gathered independently by reading general literature and literature provided by the clinic was also important for patients. Discussions with other clinic patients played a significant role, as did videos and support groups. Patients also reported gathering information from a variety of other sources, including discussions with specialists, clinic staff, family, friends, and spouses.

Overall, the range of activities engaged in shows the importance patients attached to the decision to attend a fertility clinic. A majority consulted more than one source of information, and considerable importance seems to have been given to information sources that would support independent decision making, such as general reading. As will be seen later, completeness of information in all areas is a key factor in patient satisfaction and, the data suggests, in the actual success of treatments.

Table 3.4 Type of Information Gathered Before Going to Clinic,* by Treatment Type (%)

	Treatment type			
	IVF	AIH	AID	Other treatments
Discussed with family physician	36	45	42	39
Discussed with gynaecologist	60	50	37	43
Read general literature	47	40	40	41
Read literature from clinic	26	16	13	10
Discussed with past/current patients	18	21	10	17
Watched video	14	8	6	5
Other	10	4	11	8
None of the above	9	10	16	13
Discussed with support group	3	2	3	1

* Multiple responses were possible. Fifty-one percent of patients checked two or more sources, 37% checked one source, and 11% did not gather any information.

Motives for Attending a Clinic

It is important to consider what motives people have for attending fertility clinics because of concerns put forth in recent years regarding NRTs and the ability of women to retain control over their bodies in making reproductive decisions. Patients (more than 99% of whom were women) were asked about the importance of different motives (e.g., their personal desire for children, that of their spouse or family) in their decision to undertake fertility treatments.

More than 9 out of 10 women in all treatment groups reported that the strongest motive for attending a fertility clinic was their own desire for children. The second most frequent motive was the desire of their spouse/partner for children. Pressure from family and from friends was a much less important motive, overall, for patients to seek treatment. Support from family and friends was a factor of moderate importance in the decision of most patients to attend fertility clinics (possibly very significant to a minority of patients).

Overall, these results suggest that, for most women, the decision to obtain treatment from a fertility clinic is based on strong personal motives, and that treatment represents their own decision. This is not to ignore the fact that a minority of women may undergo fertility treatment under social pressure from a spouse/partner or family members. However, decisions under such conditions are not unique to fertility treatments; that is, they are not different from general reproduction decisions, which usually do not involve NRTs.

Table 3.5 Motives for Patient Decision to Attend Fertility Clinic, by Treatment Type (%)*

	Treatment type			
	IVF	AIH	AID	Other treatments
Your own desire for children				
Not important	0	0	0	0
Somewhat unimportant	0	0	1	0
Somewhat important	2	0	0	3
Important	8	4	3	7
Very important	91	96	96	91
Spouse/partner's desire for children				
Not important	1	0	1	1
Somewhat unimportant	2	1	5	3
Somewhat important	9	18	11	5
Important	15	9	17	17
Very important	73	73	67	74
Family members' pressure				
Not important	67	65	64	67
Somewhat unimportant	12	17	11	17
Somewhat important	13	13	13	10
Important	6	3	8	5
Very important	2	3	4	1
Family members' support				
Not important	29	44	32	27
Somewhat unimportant	9	8	11	11
Somewhat important	29	22	25	32
Important	16	12	20	18
Very important	17	15	13	13
Friends' pressure				
Not important	83	76	75	78
Somewhat unimportant	10	11	14	9
Somewhat important	5	8	6	8
Important	1	1	2	3
Very important	1	4	2	1
Friends' support				
Not important	42	49	41	36
Somewhat unimportant	12	19	16	18
Somewhat important	25	15	21	23
Important	10	8	14	15
Very important	11	10	8	7

* Figures may not add to 100% due to rounding.

Beginning Treatment

As we noted earlier, a great deal of time often elapses between the patients realizing that they have a fertility problem and then doing something about it (seeking a diagnosis or treatment). Patients also reported that the time period between the first contact with the fertility clinic and the start of treatment varied — from starting treatment immediately to delays of several years. This probably reflects both waiting time for clinics in high demand and the complexity of patient decision making. (Stephens's survey of fertility programs indicates that the usual wait for an assessment varied from six to thirty weeks but that usually not more than a few months elapsed between the assessment and the start of treatment.)

Patients' Expectations

Patients' expectations at the start of treatment were examined and compared to the reports of the probability of success that patients indicated the clinics provided to them (Table 3.6). Patients' confidence that treatments would result in a child was high — regardless of the chance of success described to them by the clinics. Over half the patients in all treatment groups indicated they were confident or very confident that they would have a baby as a result of their treatment (this is similar to Wright's findings).²⁵

Nearly all IVF patients said that the clinic provided an estimate of the probability of becoming pregnant or of having a baby. Some patients also said that the clinic provided other information. For example, success rates (as a percentage) were sometimes provided with the denominator being the number of treatments, but patients were "unsure how it applied." Others were told that their treatment had a "high success rate," that there were "no guarantees," and that they had "a low chance due to low sperm count." Patients reported that IVF fertility clinics usually estimated the chance of having a baby as less than 25%. AIH, AID, and "other treatment" patients were far less likely to receive a particular estimate of success than IVF patients, but a majority of patients of AIH and AID clinics that did receive an estimate of success reported that the estimate was more than 25%. It is evident that estimates of "success" are not provided in any standard way by clinics.

Table 3.6 Information Received by Patients Regarding Likelihood of Success of Treatments and Patients' Confidence of Success, by Treatment Type (%)*

	Treatment type			
	IVF	AIH	AID	Other treatments
Told about chance of pregnancy	80	47	55	46
Told about chance of having a baby	73	33	41	29
No estimate of chance of success was given	8	39	25	45
Given other indications of what to expect	8	14	18	9
Told the chance of pregnancy was				
1% - 25%	82	43	34	38
26% - 50%	15	37	31	27
51% - 100%	2	21	35	34
Told chance of having a baby was				
1% - 25%	93	43	28	32
26% - 50%	5	37	28	31
51% - 100%	2	21	44	37
Confidence that treatments would result in a child				
Not confident at all	6	2	0	4
Not confident	6	5	9	8
Uncertain	36	29	19	35
Confident	25	31	29	24
Very confident	27	33	43	30

* Figures may not add to 100% due to rounding.

Part 4. Diagnoses, Treatment, and Counselling

Fertility Problems

The majority of patients in all treatment groups had received a diagnosis of their fertility problem at or by the time they started attending the fertility clinic (Table 4.1). Patients reported a wide range of diagnoses. Additionally, a substantial minority of those receiving a diagnosis (about one in three) were diagnosed as having multiple fertility problems. However, a notable minority of patients experienced unexplained infertility (see Table 4.1). The fertility problems of this latter group remained unexplained at the time they began treatments, often after a string of

consultations that might have included seeing family physicians/general practitioners, gynaecologists, specialists, and one or more fertility clinics.

Among patients in IVF treatment, the most predominant fertility problems — noted in over half of them — were with fallopian tubes. Among AIH patients many different problems were identified, including problems with sperm, egg production, endometriosis, fallopian tubes, and menstruation. The most common diagnosis among patients receiving donor insemination was problems with sperm (as expected).

Table 4.1 Diagnoses, by Treatment Type (%)

	Treatment type			
	IVF	AIH	AID	Other treatments
Cause				
No cause identified	23	34	7	32
Specific diagnosis or diagnoses	77	66	93	68
Number of diagnoses*				
Single diagnosis indicated	68	68	74	67
Multiple diagnoses indicated	32	32	26	33
Specific diagnoses**				
Problem with egg production	15	21	5	33
Sperm problem(s)	16	30	73	19
Endometriosis	20	19	15	15
Problem(s) with fallopian tubes	53	17	4	12
Problem(s) with menstruation	4	12	3	8
Problem(s) with uterus	3	5	0	5
Cervical mucus problem	2	10	4	6
Other problem	18	18	24	17

* Percentages based on subsample of patients reporting specific diagnosis or diagnoses. For example, among IVF patients with a specific diagnosis or diagnoses, 32% reported multiple diagnoses.

** Percentages based on *total number* of patients in each treatment group. Multiple responses were possible.

Treatments Considered and Given

Patients reported that doctors at their clinics identified a wide range of possible treatments (Table 4.2). In many cases they reported having received more than one type of treatment (e.g., combined treatments or progression from one treatment to another over a number of years). There

was a close correlation between the treatments initially identified as possible by doctors and then recommended, and treatments actually given.

For 41% of IVF patients the clinic recommended that IVF be combined with fertility-drug treatments. For the vast majority of AIH patients, many of whom had multiple diagnoses, the recommendation was AI combined with fertility drugs (or sperm wash/intrauterine insemination (IUI).) For AID patients, many of whom also had multiple diagnoses, the recommendation was often donor insemination with fertility drugs, and, in a minority of cases, with sperm wash/IUI. For patients receiving other treatments a wide range of treatments was recommended, but fertility drugs were most frequently reported among this group.

Table 4.2 Treatments Indicated as Possible,* Recommended,* and Given by Clinic,* by Treatment Type (%)

	Treatment type			
	IVF	AIH	AID	Other treatments
Doctor indicated treatment was possible				
Fertility drugs	45	85	34	76
AIH	20	92	18	27
AID	11	15	100	10
IVF	96	35	19	35
Other treatment	37	88	36	67
Doctor recommended treatment				
Fertility drugs	41	79	33	73
AIH	12	89	10	10
AID	6	6	99	3
IVF	93	12	6	13
Other treatment	29	77	29	62
Treatment was given by clinic				
Fertility drugs	45	83	50	75
AIH	10	100	13	0
AID	5	0	100	0
IVF	99	0	0	1
Other treatment	27	75	31	60

* Multiple responses were possible.

Counselling and Other Support

Other studies have placed considerable importance on several aspects of counselling and patient support, and these were examined in this

survey.²⁶ For the purposes of the survey, we included formal counselling and less formal discussions, counselling provided to the patient, counselling provided to the spouse/partner, as well as opportunities to discuss treatment decisions with other patients or people who were not connected to the clinic. As shown below, many patients included counselling by the doctor and other clinic staff in their reports of “counselling,” thus they did not see counselling only as a service provided by professional counsellors or social workers.

A majority of patients reported receiving counselling or support of one kind or another (Table 4.3). More specifically, about nine in 10 patients were given counselling or had someone to talk to about the treatment but their spouses/partners had fewer counselling opportunities. Patients in the “other treatments” group were given substantially less counselling. Nearly one third of AI patients and their spouses/partners were not offered counselling of any type; and more than half the patients and their spouses/partners in the “other treatments” group were not offered counselling or did not have informal discussion/supports.

Table 4.3 Counselling Services Provided to Patients,* by Treatment Type (%)

	Treatment type			
	IVF	AIH	AID	Other Treatments
Counselling for yourself	75	53	50	36
Counselling for your partner	67	49	42	31
Time to discuss decisions with other patients	77	54	33	27
Time to discuss treatment with an independent person	50	26	29	19
Received any of the above	89	70	66	46

* Multiple responses were possible.

Follow-up Survey on Counselling

The patients’ responses to the questions on counselling left a number of issues to be clarified. For example, from the initial patient survey data it was not entirely clear how patients defined counselling — whether they interpreted it to mean only formal counselling by a psychologist or social worker, or (as the research team suspected) whether they included contact or discussions with, for example, doctors or nurses in the clinics.

To clarify these issues we conducted a small follow-up survey with patients in two clinics. We asked these patients whom they received counselling from, and if they reported in the survey that they wanted more counselling, whom they wanted to have more counselling from. The results of this follow-up survey indicate that patients were most likely to have received counselling from a clinic physician or nurse, and less likely to have received counselling from a psychologist or social worker. When patients indicated that they wanted more counselling, most meant that they wanted more counselling from the physician (and, to a lesser extent, the nurse). Next in frequency were those who wanted more counselling from a psychologist or social worker.

The Costs of Fertility Treatments

Patients reported incurring substantial costs in their pursuit of fertility treatments, particularly IVF (Table 4.4). IVF patients reported average total costs of about \$3 700 per cycle, consisting primarily of direct fees to the clinic averaging about \$1 800; fertility drugs averaging about \$1 100; and travel averaging about \$300. They reported indirect costs for such things as time lost from work at an average of about \$500. IVF patients who had completed treatment reported average total costs of about \$7 000 before reimbursements from insurance and about \$5 600 after reimbursements. AI patients who had completed treatment reported substantially lower costs of treatment per cycle but fairly high costs overall, at an average of about \$3 200 for AIH and \$2 500 for AID. The costs to patients outside Ontario for IVF treatments were generally much higher because IVF is covered by OHIP, whereas in other provinces it is not (see Figure 9.2A).

Table 4.4 For Patients Who Have Ended Treatment, Direct and Indirect Costs of Treatment Per Cycle and Total Cost, by Treatment Type

	Treatment type			
	IVF	AIH	AID	Other treatments**
Average costs per cycle				
Paid directly to clinic	\$1 771.51	\$181.55	\$232.25	-
Drugs and other costs	\$1 095.48	\$460.51	\$90.69	-
Other direct, e.g., travel	\$273.85	\$77.50	\$51.39	-
Indirect costs, e.g., lost work	\$525.78	\$145.62	\$86.17	-
Total costs per cycle	\$3 666.61	\$865.18	\$460.50	-
Total (overall) costs*	\$7 221.74	\$3 267.65	\$2 586.54	\$2 257.51
Total costs less repayments***	\$5 601.00	\$1 757.00	\$2 247.00	\$1 714.00

Table 4.4 (cont'd)

	Treatment type			
	IVF	AIH	AID	Other treatments**
Average number of cycles	2.00	4.03	6.23	-

* Some patients only reported total costs of treatment and their results have been included in the calculation of total (overall) costs. Consequently, total (overall) cost results vary slightly from the total costs that would be calculated from multiplying total costs per cycle by average number of cycles.

** Per cycle costs were not computed for patients in the “other treatments” group, since most of these patients did not report cycles.

*** For example, benefit payments from health insurance, employers, etc.

Total Time Elapsed

Patients of fertility clinics are generally in search of answers and treatment, and they are often in treatment for a long time.²⁷ The process, from suspecting a fertility problem to attending and completing treatment at a fertility clinic, is summarized in Table 4.5. On average, between the patient first suspecting a fertility problem and going for a diagnosis, a period of eight months elapsed.²⁸ Between the diagnosis and going to a fertility clinic, a period of one to two-and-a-half years elapsed. (In this period other fertility treatments were often obtained from other sources). The average treatment time was between one and two years, and the total average time (for those who had ended their treatments at a given clinic) between initially suspecting a fertility problem, going to a clinic, and completing treatment was between four and six years.

Table 4.5 Average Time Elapsed During Each Step in Undertaking Treatment, by Treatment Type

	Treatment type			
	IVF	AIH	AID	Other treatments
Months taken to get a diagnosis	6.95	4.30	12.48	7.18
Months between diagnosis and going to clinic	30.90	21.61	16.15	16.51
Months before starting treatment	12.91	4.43	8.10	4.39
Months in treatment	20.09	21.21	22.71	20.54
Total months in process (if treatment ended)	68.00	49.00	53.00	46.00

Part 5. Information Received and the Decision-Making Process

The Quality of the Information Provided by Clinics

Fertility clinics vary widely in how much information and what type of information they provide to patients. The survey responses were examined in terms of patient satisfaction, to determine how well clinics appear to be meeting patients' needs for information. This was measured by computing an overall satisfaction score.²⁹

IVF patients indicated the highest level of satisfaction (over 70% satisfied) with information provided on issues such as the chances of a multiple pregnancy, the direct financial costs, consent forms, and the handling of extra eggs and embryos (Table 5.1). AIH patients, AID patients, and "other treatment" patients rated most areas of information as only moderately satisfactory. It is striking that in all groups information about adoption was least likely to be given and least likely to be satisfactory.

Table 5.1 Proportion of Patients Reporting Various Types of Information as Having Been Provided by the Clinic and as Having Been Better-than-Adequate to Excellent in Quality* (%)

	Treatment type			
	IVF	AIH	AID	Other treatments
Information about the fertility problem	52	42	60	44
Adoption as an alternative	12	3	8	6
Treatment alternatives, choices	60	48	51	46
Live birth rates of this clinic	64	23	36	24
Live birth rates of specific procedures	55	19	39	23
Your personal chances of having a baby	48	31	43	34
Information on qualifications of staff	47	25	40	26
Short-term effects of treatment	56	47	33	38
Long-term effects of treatment	33	26	25	28
What you had to do to succeed	65	38	31	46
Specific risks to a child	43	18	26	20
Chance of a multiple pregnancy	81	59	37	51
Direct total financial costs	75	48	45	36
Indirect financial costs	55	33	18	24
Demands of treatment on time	71	44	29	32
Physical demands of treatment	61	31	28	32
Emotional demands of treatment	58	25	23	25
Demands on relationship with spouse/partner	50	22	28	24
Use/handling of extra eggs	71	11	5	12
Use/handling of extra semen	42	13	10	6
Use/handling of extra embryos	70	11	3	7
Consent forms to be signed	76	24	51	26

* Multiple responses were possible.

Two points stand out in these results. First, while the clinics provided high-quality information on a number of the topics that are important to patients, many areas of information rated as important by patients appear to be a lower priority for fertility clinics. Less than half the patients in all groups (including IVF patients) were satisfied with the kind of information provided about their chances of having a baby, and less than one-third were satisfied with the kind of information on the long-term effects of drugs and treatments. Second, the data suggest that clinics generally performed better in providing information to IVF patients than to patients in other treatment groups. This difference between IVF and other patients emerges clearly in a wide range of patient assessments.

What Type of Information Is Important?

Patients were asked to rate the importance of various types of information. Asked to evaluate which types of information they felt it was particularly important for a patient to have, they assigned high importance to several types of information. In particular, a high rate of importance (rated important by 70% or more of all patients) was assigned by patients in all treatment groups to information about their fertility problem, their chances of having a baby, the emotional demands of treatment, the short-term and long-term effects of treatment, and the treatment alternatives.

It is significant that the information that patients considered most important was generally different from the information that clinics were judged as performing exceptionally well in providing. Generally, the information that patients wanted *most* was not the information that clinics were providing — there was a mismatch, as is evident from comparing Tables 5.1 and 5.2.¹

There is little doubt that most fertility clinics provide important information and that the information they provide most successfully on topics such as multiple pregnancies, direct financial costs, consent forms, and the handling of extra eggs and embryos is extremely important from a public policy perspective. Yet the information that patients wish to have is, without doubt, also an important component of informed decision making. The gaps noted here should therefore be of concern to practitioners as well as policy makers. Of course, the clinics may not have the capability to provide some of the information that patients want. For example, if patients want more information on the diagnosis of their fertility problem or the effects of treatment, they may be running up against the limits of current knowledge about NRTs. Clinicians may simply not have all the answers that patients want. It also may be that clinics simply have had to prioritize efforts given to provision of various types of information because of limited resources.

Table 5.2 Proportion of Patients Rating Various Types of Information as Important to Them, by Treatment Type* (%)

	Treatment type			
	IVF	AIH	AID	Other Treatments
Information about the fertility problem	77	92	78	88
Adoption as an alternative	35	24	31	37
Treatment alternatives, choices	71	76	73	75
Live birth rates of this clinic	69	54	57	43
Live birth rates of specific procedures	66	60	59	60
Your personal chances of having a baby	85	77	80	84
Information on qualifications of staff	52	40	50	50
Short-term effects of treatment	80	75	67	81
Long-term effects of treatment	82	73	66	83
What you had to do to succeed	67	57	58	67
Specific risks to a child	74	67	68	72
Chance of a multiple pregnancy	64	63	48	63
Direct total financial costs	70	67	66	60
Indirect financial costs	47	45	29	41
Demands of treatment on time	59	48	53	48
Physical demands of treatment	74	70	54	69
Emotional demands of treatment	81	70	72	73
Demands on relationship with spouse/partner	57	60	52	61
Use/handling of extra eggs	60	37	26	36
Use/handling of extra semen	51	37	27	35
Use/handling of extra embryos	64	37	28	37
Consent forms to be signed	53	45	44	42

* Multiple responses were possible for these questions.

Decision Making

Along with information and the quality of services, decision making was a key focus of this study. How are decisions made? What is the patient's role? How satisfactory is the decision-making process to the patient? As noted earlier, many patients (particularly IVF patients) gave their fertility clinic a good rating on such decision-making aspects as "time to think before making decisions" and "time to discuss decisions with the partner." This evidence pointing to a relatively strong satisfaction with the decision-making process, is further supported by direct questioning of patients regarding decision making. Generally, patients reported that decisions such as what the options were and what treatments to have were made jointly by the doctor, the patient, and the partner in the early stages of treatment (see Table 5.3). Patients and partners were more likely to be the decision makers as treatment progressed, and decisions as to when to

end treatment were most often made by patients and their partners alone. Few patients reported that the doctors made all of the decisions alone.

Table 5.3 Decision Making in Fertility Treatments, by Treatment Type (%)^{*}

	Treatment type			
	IVF	AIH	AID	Other treatments
Treatment options were/are				
Patient and partner decided	13	11	12	11
Patient/partner decided with doctor	69	65	66	62
Doctor decided	18	24	21	26
Which treatment(s) to have				
Patient and partner decided	23	18	27	14
Patient/partner decided with doctor	60	59	59	62
Doctor decided	17	23	15	24
When to continue/stop treatment(s)				
Patient and partner decided	53	49	49	48
Patient/partner decided with doctor	37	39	39	31
Doctor decided	10	12	12	21

^{*} Figures may not add to 100% due to rounding.

Consent Procedures

Overall, the most significant feature of patients' reports of consent procedures was the more elaborate and numerous consent procedures reported for IVF and AID patients compared with AIH and "other treatment" patients (Table 5.4). Generally, IVF patients were likely to experience an extremely rigorous consent protocol (with some specific gaps). Nearly all IVF patients reported a wide range of informed consent procedures. Most AID patients reported similarly rigorous consent procedures, although with slightly fewer consent procedures than IVF patients.

Perhaps understandably, AIH patients reported few formal informed consent procedures. The "other treatments" group was not homogeneous and reported a relatively less formal protocol for consent. Patients in all treatment groups considered consent procedures to be weakest in the areas of "being told that consent could be withdrawn," and being "given copies of signed consent forms." There are two major reasons which may account for this variation in consent procedures. First, a substantial proportion of IVF treatments are offered in the most "procedurally correct" fertility clinics — the six fertility clinics (five of which are in Canadian teaching hospitals) that, according to the survey, are models of excellence in their provision of

information, their procedures, and their treatment. Second, there is a tendency in all fertility clinics to handle IVF and AID treatments somewhat more rigorously than AIH and “other treatments,” given the invasive nature of IVF and the issues raised by introducing donor gametes.

As context, it should be remembered that consent is often not required for therapeutic protocols for clinical problems whose complexity is comparable to that of IVF and AID, such as the initiation of blood-pressure therapy, diabetic day-care, or even cancer chemotherapy (in some hospitals).

Table 5.4 Types of Consent Procedures Followed by Clinic,* by Treatment Type (%)

	Treatment type			
	IVF	AIH	AID	Other treatments
Asked to sign any consent forms	97	48	96	53
Asked to sign consent forms before treatment	90	46	87	47
Fully explain purpose of consent forms	96	43	95	49
Time to ask questions about consent forms	96	39	92	46
Told patient could withdraw consent	78	27	53	25
Given privacy to discuss consent forms	94	39	89	37
Given time to discuss consent forms	94	42	91	38
Given copies of signed consent forms	59	6	22	11

* Multiple responses were possible.

Part 6. Clinic Services

The Quality of Clinic Service

Patients were asked to assess the quality of clinic services in 20 performance areas (Table 6.1). Patients’ ratings of the quality of different services varied. The most highly rated aspect of clinic performance indicated by all four treatment groups was respect for confidentiality. IVF patients rated the quality of service highly in such areas as respect for confidentiality, respect for privacy, time to discuss decisions with spouse/partner, treatment for themselves, time to think before making decisions, and clinic staff support and understanding.

Generally, the high degree of satisfaction noted for IVF patients reflects the impact of (1) the generally higher quality of treatment provided by clinics to IVF patients; and (2) the particular institutional strengths of a

number of the fertility clinics tending to specialize in IVF. In contrast, patients receiving AIH, AID, and “other treatments” reported a much lower level of satisfaction with clinic services. In particular, counselling for their spouses/partners was seen as unsatisfactory by a great majority of all patient groups.

Table 6.1 Proportion of Patients Rating Various Aspects of Services as Having Been Provided by the Clinic and as Having Been Good to Excellent in Quality,* by Treatment Type

	Treatment type			
	IVF	AIH	AID	Other treatments
Treatment for yourself	75	53	64	61
Treatment for your spouse/partner	56	40	29	34
Information sessions with clinic staff	61	32	31	27
Written information	65	35	26	31
Videotaped information or material	33	9	1	6
Counselling for yourself	35	13	23	10
Counselling for your spouse/partner	31	10	18	10
Time to think before making decisions	73	48	62	53
Time to discuss decisions with spouse/partner	76	55	63	57
Time to discuss decisions with clinic staff	69	41	52	50
Time to discuss decisions with other patients	40	23	13	9
Time to discuss treatment with an independent person	26	8	12	8
Time spent waiting at the clinic	44	31	34	35
Continuity and consistency of clinic service	64	49	47	52
Ongoing information the clinic provided	61	29	38	36
Comprehensiveness of clinic facilities	65	58	49	61
Comfort and pleasantness of clinic facilities	64	57	50	53
Clinic staff support and understanding	72	46	60	50
Respect for your privacy	78	56	74	66
Respect for your confidentiality	84	66	77	73

* Multiple responses were possible.

Importance of Various Aspects of Clinic Service

Patients were asked to rate aspects of clinic service that were particularly important to them (Table 6.2). Again, it is instructive to compare whether those services rated as most important by patients were the services for which clinics received high performance ratings. For example, this comparison indicates:

- All patients rated treatment for themselves and clinic staff support and understanding as very important to them. IVF patients rated clinic performance high in these two areas, but the other three patient groups did not assign a high rating to clinic performance in these areas.
- Three areas were rated by patients as very important that were not top performance areas for fertility clinics: “continuity and consistency of clinic services,” “ongoing information the clinic provided,” and “time to discuss decisions with clinic staff”.
- Respect for privacy and confidentiality was a particularly important concern for AID patients and these patients rated performance by clinics as very good in this area.
- Treatment of the spouse/partner was especially important for IVF and AIH patients compared with AID patients, but performance of clinics in this regard was rated as less than good to excellent by a significant proportion.

Table 6.2 Proportion of Patients Rating Various Aspects of Clinic Service as Important to Them,* by Treatment Type (%)

	Treatment type			
	IVF	AIH	AID	Other treatments
Treatment for yourself	86	90	80	86
Treatment for your spouse/partner	67	68	47	69
Information sessions with clinic staff	68	54	50	60
Written information	59	59	57	62
Videotaped information or material	31	30	21	28
Counselling for yourself	49	45	44	47
Counselling for your spouse/partner	42	38	33	41
Time to think before making decisions	59	52	56	66
Time to discuss decisions with spouse/partner	56	54	56	66
Time to discuss decisions with clinic staff	78	70	75	78

Table 6.2 (cont'd)

	Treatment type			
	IVF	AIH	AID	Other treatments
Time to discuss decisions with other patients	42	38	33	36
Time to discuss treatment with an independent person	28	34	27	34
Time spent waiting at the clinic	66	59	66	64
Continuity and consistency of clinic service	79	78	74	78
Ongoing information the clinic provided	86	81	72	85
Comprehensiveness of clinic facilities	62	53	50	56
Comfort and pleasantness of clinic facilities	57	48	51	49
Clinic staff support and understanding	85	73	78	86
Respect for your privacy	68	64	80	75
Respect for your confidentiality	67	69	83	74

* Multiple responses were possible.

The Match Between the Clinic's Performance and the Patient's Needs

A variety of comparisons have been made between the information and services provided by fertility clinics on the one hand, and the importance assigned to these by patients on the other. To affirm these comparisons, patients were asked *directly* about the quality of the match in three areas: decision making, information, and counselling (Table 6.3).

Patients' responses to these questions complement the findings regarding information and decision making, and introduce new information in the area of counselling in particular. Most patients reported that their participation in decision making was "just right." Only a minority of patients reported that their participation was "not enough." On the other hand, "information about all aspects of treatment" was less positively assessed overall, and varied substantially across treatment groups. For example, only in the IVF group did a large majority of patients report that information was "just right," and while a substantial minority of AID patients and "other treatment" patients reported not receiving enough information, nearly half of all AIH patients indicated that they had not received sufficient information.

Patients in *all* treatment groups reported that they did not receive enough counselling. Only IVF patients rated the counselling they received

before treatment as “just right,” while nearly half of all other groups indicated that the counselling they had before treatment was “not enough.” Further, the proportion of patients indicating that they did not receive enough counselling rose steadily as they moved toward the end of the treatment process. Overall, somewhat more than half of the patients assessed the counselling given *after* treatment as “not enough.”

Overall Assessment of Treatments and Clinics

To obtain an overall assessment of the clinic experience, the researchers asked patients whether they would “recommend fertility treatments” and whether they would “recommend the same clinic” to a friend (Table 6.4). Although it was the opinion of many patients that they received insufficient information and counselling, nearly all patients in all four treatment groups indicated that they would still recommend fertility treatments and the specific fertility clinic they attended to a friend. Only a small percentage of respondents answered other than “yes” or “no” to these questions. Some answered “yes” conditionally (“for younger women” or “for those who are well informed”); others said they “would not want to reveal own use of treatments” because it was “too personal a matter.” IVF patients were the group most strongly inclined to recommend fertility treatments and to recommend their own clinic. Non-IVF patients were only slightly less likely to recommend their clinic to a friend, and those in the “other treatments” group were less likely to recommend their particular clinic.

These data suggest that while many patients had complaints about the particulars of fertility clinic services, they regarded the clinic treatments as “the best option” for their particular situation, given the limited alternatives.

Table 6.3 Meeting Patients' Needs in Decision Making, Information, and Counselling, by Treatment Type (%)*				
	Treatment type			
	IVF	AIH	AID	Other treatments
Your participation in decisions				
Not enough	9	16	8	15
Just right	90	81	90	85
Too much	1	3	2	0
Spouse's/partner's participation in decisions				
Not enough	10	19	11	14
Just right	89	81	88	85
Too much	0	1	1	0

Table 6.3 (cont'd)

	Treatment type			
	IVF	AIH	AID	Other treatments
Information about all aspects of treatment				
Not enough	23	49	30	42
Just right	76	51	69	58
Too much	1	0	1	1
Counselling before treatment began				
Not enough	26	46	36	54
Just right	72	54	61	46
Too much	1	1	2	0
Counselling during treatment				
Not enough	35	54	60	59
Just right	64	45	39	41
Too much	1	1	1	0
Counselling after treatment				
Not enough	49	62	55	65
Just right	50	38	45	35
Too much	1	0	0	0

* Figures may not add to 100% due to rounding.

Table 6.4 Proportion of Patients Who Would Recommend Fertility Treatments and Clinic, by Treatment Type (%)*

	Treatment type			
	IVF	AIH	AID	Other treatments
Would you recommend fertility treatments to a friend?				
Yes	97	92	91	96
No	3	7	7	3
Other response	0	0	2	0
Don't know	0	1	1	1
Would you recommend this clinic to a friend?				
Yes	95	86	89	85
No	3	7	4	9
Other response	1	2	7	5
Don't know	1	5	1	1

* Figures may not add to 100% due to rounding.

Part 7. How Patients Concluded Their Treatment

Why Treatment was Ended

Patients ended their treatments for a variety of reasons that reflected their particular situations, levels of resources, financial resources, and physical and emotional strength (Table 7.1). The most common reason patients gave for ending treatment themselves was because they became pregnant. The next but considerably less frequent reason was because of stress. This was followed by a wide variety of other considerations, including costs. Other common reasons cited by patients for ending treatment included such factors as “getting too old,” “lack of results,” “didn’t like clinic,” “went to another clinic,” and “moved to another city.” Most IVF patients who did not become pregnant seemed to pursue treatment to the end of their emotional, physical, and/or financial resources (Table 7.1).

Table 7.1 Whether Treatment is Ongoing or Ended and Reasons Patients Ended Treatment, by Treatment Type (%)

	Treatment type			
	IVF (450)	AIH (90)	AID (90)	Other treatments (180)
Percentage for whom treatment is concluded	62	59	51	59
Who ended treatment?*				
Clinic ended treatment	6	4	4	5
Other (e.g., ended at conclusion of cycle)	32	16	6	13
Patient ended treatment	24	39	41	40
Reason <i>patient</i> ended treatment**				
Pregnancy	11	13	27	19
Adopted a child	2	0	2	2
Psychological/emotional stress	5	13	5	10
Physical difficulties	3	6	3	6
Costs	4	8	7	4
Other	8	16	5	13

* Percentages based on total number of patients in each treatment group.

** Percentages based on total number of patients in each treatment group and multiple responses were possible.

How Treatment Was Ended

In considering how treatment was ended, the SPR research team examined the issue of success as perceived by patients and the actual process involved in ending treatment (e.g., whether there were exit interviews, see Table 7.2). Among patients whose treatment was concluded, indicators of success were varied. About half of these patients reported that the treatments were successful — some meant by this having a baby, some meant becoming pregnant, and some had other definitions of success. Different individuals regarded a wide range of outcomes as relative successes. For example, many patients identified pregnancy as “success” even when it ended in a miscarriage. Some others credited the program when they conceived on their own after the treatment ended. Other patients reported such things as “satisfaction at having tried all options,” and “achieving better understanding of own situation” as success. More than half of IVF, AID, and “other treatment” patients who had ended treatment reported some type of success. Slightly less than half of AIH patients reported some type of success. Specific successful outcomes, such as pregnancy or actually having a baby, were least likely among AIH patients.

The majority of patients for whom treatment was ended concluded it without an exit interview. Only about four in ten of IVF and “other treatment” patients who concluded their treatment reported having an exit interview. AID and AIH patients were the least likely to receive an exit interview — only about 2.5 in 10.

Table 7.2 Proportion of Patients Reporting Various End-of-Treatment Experiences, by Treatment Type (%)

	Treatment type			
	IVF (450)	AIH (90)	AID (90)	Other treatments (180)
Percentage for whom treatment is concluded	62	59	51	59
Success of treatment*				
Had baby	24	7	25	17
Pregnant now	19	17	31	25
Neither of the above	45	52	27	39
Other success	11	17	10	13
Was there a last or exit interview with clinic staff?*				
Yes	39	22	27	41
No	56	71	67	56

* Percentages based on subsample of patients for whom treatment is concluded. For example, among the 62% of IVF patients who had concluded treatment, 24% of patients indicated that their treatment was a success because they had a baby. (Percentages may not add to 100% due to missing data).

Follow-up Counselling

Nearly half of patients for whom treatment had ended said no follow-up counselling was offered (Table 7.3). A majority of these patients in each treatment group would have desired this (61% to 81%), even though a substantial minority in each group did not (19% to 39%). Although offering more counselling is desirable, not every patient would want to use it.

Among patients for whom post-treatment counselling was provided:

- those who had concluded their treatment were most likely to receive counselling regarding pregnancy/birth (about one in five for those becoming pregnant);
- patients who had concluded their treatment were next most likely (after counselling regarding pregnancy/birth) to receive counselling regarding other fertility treatments (about one in ten);
- very few of those who had concluded their treatment received counselling regarding adoption as a post-treatment option; and
- although about one in six of IVF patients who had concluded their treatment received counselling in dealing with the emotional stress of treatment and of coming to terms with not having a child, only a very small percentage of AIH, AID, and “other treatment” patients received counselling in this area.

Table 7.3 Type of Follow-up Counselling Provided,* by Treatment Type (%)

	Treatment type			
	IVF	AIH	AID	Other treatments
Percentage for whom treatment is concluded	62	59	51	59
Types of counselling received*				
Pregnancy/birth	18	19	18	19
Adoption as an option	5	7	0	2
Other fertility treatment choices	10	17	4	15
Dealing with emotional effects of treatment	16	3	2	5
Received any type of follow-up* counselling	35	39	23	39
No follow-up counselling offered*	42	51	43	46
No follow-up counselling desired*	32	19	39	27

* Percentages based on subsample of patients for whom treatment is concluded: IVF (450), AIH (90), AID (90), “other treatments” (180). For example, among the 62% of IVF patients who had concluded treatment, 18% reported they had received counselling on pregnancy/birth. Multiple responses were possible.

Attitudes Toward Adoption During and After Treatment

In Part 2 we examined the extent to which patients were likely to pursue adoption prior to fertility treatment. In this section we examine patients' attitudes toward adoption during treatment (Table 7.4). We hypothesized that, as time passed during their treatment, a substantial number of additional patients would take steps toward adoption.

This hypothesis was modestly supported by patients' responses, with a small but noticeable group taking new steps to adopt during or after treatment. For example, 20% of IVF patients had reported applying for adoption prior to treatment, but the proportion having taken some steps toward adoption rose to about 30% during and after the treatment process. A majority of IVF patients and about half of all other patients had either considered adoption or taken steps to begin adoption by the time treatment was under way or completed. After treatment ended 40% of patients still did not wish to consider adoption. It should be borne in mind that the probability of successfully adopting during treatment — estimated here at about 2% — is likely to be even smaller than the probability of becoming pregnant.

Table 7.4 Whether and When Patients Considered Adoption, by Treatment Type (%)

	Treatment type			
	IVF	AIH	AID	Other treatments
Applied for adoption prior to starting treatment	20	9	14	9
If considered adoption after starting treatment				
Completed adoption	0	0	0	1
Applied for adoption but not approved	0	0	0	0
Applied for adoption and still waiting	10	17	7	6
Applied, other (e.g., withdrew later)	4	1	6	4
Considered adoption but did not apply	25	24	29	33
Did not consider adoption	41	49	44	47

Attitudes Toward Future Treatment

In spite of the experiences of many patients — who received treatment in many settings, and often despite significant financial costs, physical and emotional stress, sometimes over many years — about three quarters of the patients indicated a readiness to continue with fertility treatments until they achieved their goal or until there could be no hope of success (Table 7.5). Asked what approaches to having a child they would consider, about

three quarters indicated that they would follow various avenues in trying to have a child. Of these:

- 58%-65% of each treatment group indicated that they were prepared to continue with their current clinic;
- about 30% indicated that they had already begun or were prepared to begin the process of adoption;
- a small minority (about one in eight) indicated that they were prepared to seek treatment from another clinic; and
- others (a smaller number) indicated that they were considering a variety of approaches, including treatment outside Canada, going to other specialists, and surrogacy.

Table 7.5 Approaches to Treatment that Fertility Patients Would Consider in Future, by Treatment Type (%)

	Treatment type			
	IVF	AIH	AID	Other treatments
No further fertility treatment	28	23	24	24
Continue with current treatments	58	62	65	60
Fertility treatment with a private practitioner	4	8	3	9
Treatment at another clinic	16	14	13	11
Other treatment with a general practitioner	1	2	0	2
Other treatment with a specialist	6	11	3	6
Other treatment outside Canada	4	5	4	5
Pursuing adoption now	20	18	10	9
Will pursue adoption in future	16	16	13	21
Surrogacy	6	5	0	3

* Multiple responses were possible.

Part 8. The Psychosocial Impact of Fertility Treatment on Patients and their Spouses/Partners

Positive Effects of Treatment

Patients reported that fertility treatments had a variety of psychosocial impacts on them, some positive and some negative (Table 8.1). There were a number of differences among the treatment groups. IVF patients tended to report more positive than negative effects than did other patients. They were twice as likely to report positive rather than negative effects on their feelings about themselves, while the AIH and “other treatments” groups were as likely to report having negative as positive effects on feelings about themselves. IVF patients were six times more likely to report a positive rather than a negative effect on their relationships with their spouses/partners (61% compared with 10%). Although less marked, the three other groups were also more likely to report positive effects on their relationships with their spouses/partners. Overall, a majority reported that their relationships with their spouses/partners had been positively affected. Overall, about half the patients reported positive impacts as regards their “role in the treatment” and about their “life overall.” About only one third of AIH, AID, and “other treatments” patients reported positive impacts on feelings about themselves and about their control over their lives (47% and 41% for IVF patients). Some reports of impacts of treatment were less positive — for example, on their “feelings of privacy and dignity” — but, overall, it is very clear that reports of positive impacts far outweighed reports of negative impacts.

Difficulties Experienced by Patients

Although most patients — especially IVF patients — reported that fertility treatments had positive effects on their lives, many also reported difficulties and stresses that accompanied their treatments (Table 8.2). A large majority of patients in all treatment groups reported that they suffered emotional stress, especially the stress of failure. They also reported heavy physical demands, and more than half of the patients reported financial difficulties — both direct and indirect costs.

Effects on Spouses/Partners

In some respects, the impact of fertility treatment reported by spouses/partners was similar to that reported by patients, only more moderate in degree (Table 8.3). For example, the strongest positive impact reported was on their relationship with their spouses/partners and on their life overall; and between 21% and 33% reported a negative effect on their feelings about themselves, on their privacy/dignity, and on their control over their lives.

Table 8.1 Effects of Clinic Treatment on Patients, by Treatment Type (%)*

	Treatment type			
	IVF	AIH	AID	Other treatments
Feelings about yourself				
Positive effect	47	29	42	34
No effect	33	39	33	34
Negative effect	20	31	25	32
Feelings of control over your life				
Positive effect	41	24	42	31
No effect	25	30	18	33
Negative effect	34	46	41	36
Feelings about your role in the treatment				
Positive effect	58	40	47	46
No effect	28	41	25	32
Negative effect	14	19	28	22
Your feelings of privacy/dignity				
Positive effect	43	36	36	38
No effect	42	40	37	43
Negative effect	14	24	27	19
Your relationship with your spouse/partner				
Positive effect	61	48	53	42
No effect	29	30	28	37
Negative effect	10	21	20	21
Your life overall				
Positive effect	59	46	49	40
No effect	22	22	16	26
Negative effect	19	32	35	33

* Figures may not add to 100% due to rounding.

Table 8.2 Difficulties Experienced as a Result of Treatment as Reported by Patients, by Treatment Type (%)

	Treatment type			
	IVF	AIH	AID	Other treatments
Emotional stress on you				
Experienced difficulties	89	87	94	85
No difficulties	11	13	6	15
Physical demands on you				
Experienced difficulties	73	72	73	70
No difficulties	27	28	27	30
Emotional stress on your spouse/partner				
Experienced difficulties	74	71	76	73
No difficulties	26	29	24	27
Physical demands on your spouse/partner				
Experienced difficulties	36	46	35	38
No difficulties	64	54	65	62
Direct economic costs				
Experienced difficulties	60	54	66	44
No difficulties	40	46	34	56
Indirect economic costs				
Experienced difficulties	51	49	58	40
No difficulties	49	51	42	60
Stress of failure				
Experienced difficulties	88	89	95	91
No difficulties	12	11	5	9

It is interesting that, overall, spouses'/partners' assessments of the impact were far more likely to be negative than were those of patients. Patients' assessments of the impact were more positive than negative in every area except the area of control over their lives. Spouses/partners in all treatment groups were as likely to be negative as positive regarding the impact on their feelings of privacy and dignity, and spouses/partners in all treatment groups except IVF were more likely to report negative than positive impacts on their feelings of control over their lives. Those in the AID treatment group were more likely to report a negative impact on their feelings about themselves (a significant percentage also reported no effect on their feelings about themselves), and those in the AIH treatment group were more likely to report negative feelings about their role in the treatment.

Table 8.3 Effects of Treatment as Reported by Spouses/Partners, by Treatment Type (%)*

	Treatment type			
	IVF	AIH	AID	Other treatments
Feelings about yourself				
Positive effect	35	24	28	25
No effect	53	58	41	59
Negative effect	12	19	32	16
Feelings of control over your life				
Positive effect	32	21	24	19
No effect	44	49	47	53
Negative effect	25	31	29	27
Feelings about your role in the treatment				
Positive effect	50	29	36	42
No effect	36	37	35	38
Negative effect	14	35	29	20
Your feelings of privacy/dignity				
Positive effect	30	29	30	25
No effect	48	38	45	54
Negative effect	22	33	25	21
Your relationship with your spouse/partner				
Positive effect	65	45	46	46
No effect	25	30	33	33
Negative effect	10	25	21	21
Your life overall				
Positive effect	52	34	46	33
No effect	30	40	25	44
Negative effect	18	26	30	23

* Figures may not add to 100% due to rounding.

Partners reported experiencing many of the same difficulties and stresses as did patients (Table 8.4). About two in three of partners reported suffering emotional stress, and nearly all partners reported stress of failure as a major difficulty. While more than two-thirds of patients reported physical demands as a difficulty, only about one in three partners reported it as a difficulty. Interestingly, patients and partners assessed the difficulties experienced by their mates fairly accurately.

Table 8.4 Difficulties Experienced as a Result of Treatment, as Reported by Partners, by Treatment Type (%)

	Treatment type			
	IVF	AIH	AID	Other treatments
Emotional stress on you				
Experienced difficulties	68	56	71	69
No difficulties	32	44	29	31
Physical demands on you				
Experienced difficulties	25	41	18	27
No difficulties	75	59	82	73
Emotional stress on your partner				
Experienced difficulties	92	87	85	85
No difficulties	8	13	15	15
Physical demands on your partner				
Experienced difficulties	88	74	68	77
No difficulties	12	26	32	23
Direct economic costs				
Experienced difficulties	65	54	54	44
No difficulties	35	46	46	56
Indirect economic costs				
Experienced difficulties	45	40	32	33
No difficulties	55	60	68	67
Stress of failure				
Experienced difficulties	83	78	83	81
No difficulties	17	22	17	19

Part 9. Analytical Aspects of Fertility Clinics

Variations in Levels of Fertility Clinic Services

To more carefully assess the variation in fertility clinic services, the research team reviewed a number of survey questions that were indicators of clinic performance to determine which clinics reflected the best and worst performance according to patients' responses. There was a striking variation in clinics' performance. Patients' ratings were examined for clinic performance on selected indicators in the areas of information, decision making, and the psychosocial impact of treatments. Table 9.1A shows the ratings of patients in the best and worst clinics for each of the key

indicators. While variations in level of services were highly intercorrelated (i.e., those performing well on one indicator tended to perform well on other indicators), the clinics performing best on selected indicators were not always the same clinics. Similarly, those performing worst on key indicators were not always the same clinics. Clinics appeared to vary quite remarkably in certain aspects, for example:

- In the clinic rated least positively by patients as regards information, only 31% of their patients reported good to excellent information about their fertility problem, and in the clinic rated most positively, 79% reported receiving good to excellent information.
- The clinic with the lowest rating in the area of using written consent procedures obtained written consent from 16% of patients, while the clinic with the highest rating in this area was reported by 100% of its patients as obtaining written consent.
- The percentage of patients reporting participation in decision making as “just right” varied among the clinics, from a low of 10% for the worst clinic to a high of 100% for the best clinic.
- The percentage of patients reporting the provision of information at their clinic as “just right” varied by clinic from 42% to 93%.
- The percentage of patients reporting that the treatment had a positive impact on their lives generally varied by clinic from a low of 25% to a high of 82%.

Table 9.1A Overall Rating by Patients of Best and Worst Clinics on Selected Indicators (%)*		
Indicator	Worst Clinic	Best Clinic
Satisfied with information about their fertility problem	31	79
Satisfied with information received about qualifications of staff	19	60
Patient signed written consent forms	16	100
Quality of their own treatment was good to excellent	21	88
Participation in decision making was “just right”	10	100
Information they received was “just right”	42	93
The amount of counselling they received during treatment was “just right”	20	84
Effect of fertility treatments on their lives was positive	25	82
* Based on clinic-by-clinic tabulations, calculated separately for each indicator; numbers indicate the percentages observed in the best and worst clinic for each indicator.		

These variations in clinic ratings were summarized in an analysis of overall clinic performance (Table 9.1B). This performance indicator, based on factor analysis and generation of an overall patient evaluation score, allowed us to rank the clinics by the type of clinic and whether it is in Ontario (to consider the impact of funding).³⁰ Ontario clinics are separated from those in other provinces because Ontario is the only province where IVF is funded by provincial health insurance.

The results are dramatic and show that even clinics of the same type vary substantially in overall quality of performance or service. Clinics performing extremely well in patient assessments include clinics of all types — teaching hospitals and non-teaching hospitals/clinics, some located in Ontario and some outside Ontario. Clinics performing poorly also include a wide range of clinics — teaching and non-teaching hospitals located within and outside Ontario.

Table 9.1B Variability in Patients' Ratings of Clinic Performance

Patient ratings	Type of Organization	Location	Standardized patient ratings*
Best clinics	Teaching hospital	(outside Ontario)	1.02
	Teaching hospital	(Ontario)	1.05
	Teaching hospital	(Ontario)	0.83
	Private clinic	(Ontario)	0.73
Average clinics	Teaching hospital	(outside Ontario)	0.44
	Non-teaching hospital	(Ontario)	0.39
	Teaching hospital	(Ontario)	0.39
	Teaching hospital	(Ontario)	0.35
	Teaching hospital	(outside Ontario)	0.25
	Teaching hospital	(outside Ontario)	-0.15
	Private clinic	(Ontario)	-0.19
	Teaching hospital	(outside Ontario)	-0.27
	Teaching hospital	(outside Ontario)	-0.30
	Teaching hospital	(outside Ontario)	-0.36
Worst Clinics	Non-teaching hospital	(Ontario)	-0.57
	Teaching hospital	(outside Ontario)	-0.60
	Teaching hospital	(outside Ontario)	-0.67
	Teaching hospital	(outside Ontario)	-0.83
	Teaching hospital	(outside Ontario)	-1.04

* The standardized rating is one where the “average” clinic would be rated “0”, positive numbers indicate better-than-average performance, and negative numbers indicate less-than-average performance. These clinic ratings were derived from a factor analysis of selected indicators of clinic performance and summation of ratings for the patients in each clinic. The scores were determined by taking key characteristics such as patient satisfaction, match of information to patient priorities, extent of information, and related indicators, computing factor scores, and producing mean factor scores for each clinic. Factor analysis is a multivariate statistical technique commonly used to identify underlying indicators that describe a field of variables — in this case quality of clinic service.

The Impact of Funding on Fertility Treatments

To consider the impact of funding on the costs of and access to fertility treatments, analyses were completed on treatment costs and incomes of patients attending fertility clinics in Ontario compared with those in other provinces (Tables 9.2A and 9.2B). With respect to costs, only results for patients who had ended treatment were considered, which allowed analysis by region (i.e., Ontario versus outside Ontario) to proceed only for IVF patients and those included in the “other treatments” group.

Table 9.2A For Patients Who Have Ended Treatment, Average Cost of Treatment Inside and Outside Ontario, by Treatment Type (IVF and Other Treatments Only)*

	Treatment type			
	IVF		Other treatments	
	Ontario	Outside Ontario	Ontario	Outside Ontario
Costs per cycle/month				
Paid directly to clinic	\$861.57	\$2 681.44	-	-
Drugs and other costs	\$946.97	\$1 243.99	-	-
Other direct costs (e.g., travel)	\$208.19	\$339.51	-	-
Indirect costs (e.g., lost work)	\$334.20	\$717.36	-	-
Total costs per cycle	\$2 350.92	\$4 982.30	-	-
Total (overall) costs**	\$5 354.41	\$9 089.07	\$1 273.65	\$2 459.66
Total costs less repayments	\$3 257.00	\$7 945.00	\$910.00	\$1 887.00
Average number of cycles	2.18	1.81	-	-

* Region results for AIH and AID treatment groups not reported due to the small number of patients who had ended treatment; further breakdown of these groups into Ontario and outside Ontario resulted in subgroups too small for reliable comparison.

** Some patients only reported total costs of treatment and their results have been included in the calculation of total (overall) costs. Consequently, total (overall) costs results vary slightly from the total costs that would be calculated from multiplying total costs per cycle by average number of cycles.

Table 9.2B Family Incomes of Fertility Clinic Patients Inside and Outside Ontario, by Treatment Type (%)*

	Treatment type							
	IVF		AIH		AID		Other treatments	
	Ontario	Outside Ontario	Ontario	Outside Ontario	Ontario	Outside Ontario	Ontario	Outside Ontario
Total annual family income								
Under \$20 000	0	3	4	0	0	11	0	3
\$20 000 - \$29 000	4	4	9	7	6	5	4	11
\$30 000 - \$39 000	7	6	9	22	25	14	14	14
\$40 000 - \$49 000	10	11	0	21	6	13	14	17
\$50 000 - \$59 000	18	21	26	15	31	15	16	11
Over \$60 000	61	56	52	36	31	42	52	45

* Figures may not add to 100% due to rounding.

The costs results for IVF patients generally reflect the impact of Ontario's health insurance coverage of this procedure, although other factors may be of some significance. For example, assistance from private health insurance coverage may be more common in Ontario because unionization is higher than the national average and there is more employment with large corporations. Overall, direct costs paid to the clinic for IVF treatment were substantially higher outside Ontario, with direct costs of about \$2 700 per cycle paid to these clinics compared with about \$900 per cycle to clinics in Ontario. We also found that in Ontario patients generally pursued treatment for more cycles. It was anticipated that "other direct and indirect costs," which included transportation and time lost from work, would also be higher outside Ontario because patients in Western and Atlantic Canada must often travel a significant distance to a single clinic serving their region. These expectations were confirmed by the data for IVF patients and suggested by the data for patients included in the "other treatments" group.

The incomes of fertility clinic patients were generally higher in Ontario than in clinics outside Ontario. These results are contrary to our initial expectation, which was that public funding would make fertility treatments more accessible to lower income groups. One possible explanation for why this is not so may be that there are barriers to access in the broader health system that may deter lower income households, regardless of public funding.

Factors Affecting Patients' Satisfaction

A correlational analysis (Table 9.3) and supplementary multivariate analyses (Tables 9.3A and 9.3B) were carried out to determine what factors are most important in affecting the quality of fertility clinic services in terms of patients' satisfaction and which factors are related to success (in becoming pregnant or having a baby).³¹

These analyses indicate that many factors are significantly related to these outcomes. For example:

- Counselling by physicians, clinic staff, or specialized counselling staff and the availability of discussion/support groups played a major role in predicting patients' satisfaction, as did the total amount of information provided, the match of information and services to patients' priorities, consent procedures, and the time patients had to think about treatment decisions.
- Location in Ontario was correlated with patients' satisfaction (Table 9.3), as was location in a teaching hospital.
- The quality of educational documents (measured for English clinics only) was found to be a factor contributing to patients' satisfaction.

Table 9.3 Correlations Between Patient Satisfaction and Success (Pregnancy, Having a Baby) and Various Characteristics of Treatment

	Patient satisfaction	Success (pregnancy or baby)
Total amount of information received	0.5247**	0.0756
Time given to think	0.3059**	0.0413
Counselling given	0.5472**	0.1280**
Rating of clinic services as not too much/little	0.6270**	0.2901**
Fertility consultations prior to clinic	-0.0155	-0.0695
Fertility treatments prior to clinic	0.0839*	-0.0946*
Amount of information gathering prior to clinic	0.1545**	-0.0566
Husband/wife motive for children	0.1069**	0.0393
Support/pressure from friends and relatives	0.0236	-0.0890
Multiple fertility problems diagnosed	-0.0141	0.0006
No diagnosis given	-0.0903**	-0.0514
Number of consent procedures followed	0.3970**	0.0805
Patient assessment of quality of information	0.7949**	0.1523**
Patient priorities for information	0.0525	-0.0439
Match (for information) between patient priority and clinic	0.6479**	0.2077**
Patient satisfaction	1.0000**	0.2396**
Match (for satisfaction) between patient priority and clinic	0.7505**	0.2966**
Expectation of having a child	0.0492	0.1611**
Patient control	-0.0104	-0.0997*
Positive impact on patient	0.5049**	0.4455**
Difficulties for patient	-0.1749**	-0.1708**
Positive impact on spouse	0.4330**	0.4683**
Difficulties for spouse	-0.1566**	-0.2459**
Teaching hospital	-0.0228	0.0615
Located in Ontario	0.2938**	0.1233**
Patient education	-0.0596	0.0604
Spouse education	-0.0414	-0.0157
Total number of children at time discovered fertility problem	-0.0163	-0.0324

Table 9.3 (*cont'd*)

	Patient satisfaction	Success (pregnancy or baby)
IVF was main treatment	0.4345**	-0.0290
AIH was main treatment	-0.1211**	-0.1432**
AID was main treatment	-0.0672*	0.1199**
Total costs	0.1218**	-0.1217**
Net costs	0.1225**	-0.1010*
Time between suspecting a problem and seeking diagnosis	0.0473	0.0398
Time between seeking diagnosis and going to clinic	0.0924**	-0.0598
Time between first approaching clinic and starting treatment	0.1863**	0.0309
Treatment status at this time	-0.0624	n.a.
Time undergoing treatment	-0.0256	0.0069
Total time from first concern to present (or end of treatment)	0.1237**	-0.0377
Clinic has own counselling staff	0.1401**	0.1543**
Clinic refers outside for counselling	-0.0365	0.0226
Clinic has peer support group	-0.0463	-0.0656
Readability of patient information	0.1399**	0.1278*
Consultant rating: quality of printed materials (no analysis of Quebec clinics)	-0.2807**	-0.0792

* Statistically significant at $p < 0.01$.

** Statistically significant at $p < 0.001$.

¹ Not computed as treatment status was the same (i.e., concluded) for all patients for whom the success measure was computed.

Table 9.3A Discriminant Analysis of Patient Satisfaction*

Summary table					
Step	Action		Variables In	Wilks' Lambda	Significance
	Entered	Removed			
1	Counselling given		1	0.76869	0.0000
2	Total amount of information received		2	0.71620	0.0000
3	IVF was main treatment		3	0.70474	0.0000
4	How often spouse goes to clinic		4	0.69873	0.0000
5	Consultant rating: quality of printed material		5	0.69610	0.0000
6	Located in Ontario		6	0.69405	0.0000
7	Teaching hospital		7	0.68962	0.0000
8	Time undergoing treatment		8	0.68747	0.0000
9	Number of consent procedures followed		9	0.68508	0.0000
10	Time given to think		10	0.68389	0.0000
11	Expectation of having a child		11	0.68285	0.0000

* Seventy-five percent accuracy in classifications.

Interpreting these findings is complex. For example, does a higher quality of documents in a clinic improve the level of patients' satisfaction, or is it simply that the best clinics in terms of patient satisfaction are also those most likely to have good quality documents? These "causal" questions are difficult to resolve. It is significant, however, that the study results consistently point toward the importance of involvement in decision making, counselling, and information as predictors of patients' satisfaction generally.

The success of treatment was also examined using correlational and discriminant analysis for patients who had completed their fertility treatments. As we have seen, "success" has many meanings for patients receiving fertility treatments; here we defined it as having a baby or being pregnant as a result of treatment. It is not surprising then that the results,

as shown in Table 9.3B, indicate that a variety of factors are related to the success of treatments. These include:

- information and decision-making factors such as the match of patient information and service priorities to those of the clinic, the consent procedures, the time patients have to think about decisions, the amount of control patients have over decisions, and the readability of patient information (perhaps indicating that technically better clinics may also be better all round);
- institutional features, such as location in Ontario and/or in a teaching hospital;
- patients' expectations of having a child and spouse attendance at treatments (expectations may be conditioned by the information the couple have about their likelihood of success — those in a category with better prognosis would have greater expectations of success); and
- background/control variables, such as treatment type and months in treatment, which reflect clinical factors and the very different type of information and related aspects for the various treatments.

These results indicate that the clinics that best observe patient needs in the areas of information, counselling, and decision making are also the ones in which women more often become pregnant and have babies.

Patients' Viewpoints

Many of the patients responding to the survey appeared eager to qualify their responses with comments and insights. Major topics of concern were access to the new reproductive technologies and funding for all or part of the treatment costs. Other concerns noted by patients include the following:

- Adoption is not an easy alternative for most because of the general unavailability of babies. Patients remarked that the adoption process is difficult, often costly, and time-consuming (10-year waiting lists are not uncommon).
- Canadian fertility clinic programs emphasize the female reproductive system and need to expand their programs to better treat male factor infertility. Some respondents noted that more treatment options for male factor infertility were available in the United States than in Canada.
- It is difficult for patients living far away from the treatment centres to obtain treatment. One respondent from the north reported that there was a lack of gynaecologists in her area, which made getting gynaecological care difficult. Such couples reported that they had to face the costs of procedures, the costs of travel, and the costs of accommodation.

Table 9.3B Discriminant Analysis of Success of Treatment*,**

Summary table					
Step	Action		Variables In	Wilks' Lambda	Significance
	Entered	Removed			
1	Expectation of having a child		1	0.97779	0.0040
2	IVF was main treatment		2	0.95525	0.0020
3	AIH was main treatment		3	0.91778	0.0000
4	Located in Ontario		4	0.89621	0.0000
5	Teaching hospital		5	0.87022	0.0000
6	Readability of patient information		6	0.85892	0.0000
7	Time undergoing treatment		7	0.85037	0.0000
8	How often spouse goes to clinic		8	0.84496	0.0000
9	Time given to think		9	0.83953	0.0000
10	Number of consent procedures followed		10	0.83214	0.0000
11	Patient control		11	0.82673	0.0000
12	Patient priorities for information		12	0.82192	0.0000

* Sixty-eight percent accuracy in classifications.

** Analysis is based on subsample of patients for whom treatment is concluded.

- Some couples said that they felt very pressured by clinics to begin treatment and remarked that not enough time had been spent on diagnosis. Other respondents complained that medical staff were more concerned with the process than the patient and that they felt like numbers or guinea pigs. Still others felt they were being “sold” their treatment — that the main concern of clinic staff was “making the sale.” Some patients, on the other hand, could not praise their clinics and the quality of care they received from the doctors and the clinic staff enough.
- Patients expressed a variety of different viewpoints regarding both access to and the limitations of treatment. Some patients felt it

was unfair that they were barred from further treatment because of their age, while others felt that there should be limitations on couples who had had successful treatment in the past trying again when there were others waiting to be accepted into programs for the first time.

- Some patients commented that they should not be required to purchase expensive drugs that they may never use (drug costs are non-refundable). Many patients commented on the high cost of medication, particularly Pergonal®.
- Many patients felt that infertility is a medical condition and that it should be regarded as such by governments.
- Some patients expressed bitterness that governments fund reproductive health care such as tubal ligations, vasectomies, and abortions but not new reproductive technologies.

Part 10. Summary and Conclusions

Based on a detailed questionnaire survey of a probability sample of approximately 1 400 patients of 21 Canadian fertility clinics, this study provided an evaluation of Canadian fertility clinics from the patients' perspective. Data were obtained on a wide range of topics, including patients' backgrounds; the history of their fertility treatments; their treatment experiences with fertility clinics; their assessment of the quality of the information, services, and counselling they received; and their assessment of the psychosocial impact of the treatments. A substudy of non-respondents to the survey suggests that the results are representative of the broader population of fertility clinic patients.

The study points to a number of important conclusions regarding fertility clinics, the treatment process, and patients, including the following:

- The fertility treatment process is complex and likely to involve many steps for those who become patients. Patients received a wide range of consultations and treatments and had treatment histories that sometimes spanned many years as they went from one specialist or clinic to another. This suggests that patients are deeply committed to finding solutions to their fertility problems.

It is noteworthy that patients were often unable to obtain a speedy assessment or diagnosis of their fertility problem and went from one physician or specialist to another before obtaining a diagnosis. These delays defer couples' clear understanding of their fertility problem while they continue to grow older and miss important options in fertility treatments and adoption.

Women with less education and lower incomes take longer, on average, to identify their fertility problems than do more educated women and those from higher income families. This suggests that women who have fewer resources may be less effective consumers, or may obtain less satisfactory service from the health care system in dealing with their fertility problems. It also points toward important issues in access to fertility treatment, which hinge not on the cost of treatments per se but, rather, on the effectiveness of the larger health care system in informing couples of their situation.

- People seeking treatment at fertility clinics are motivated by many things, but the most important is the patient's personal desire for children. Other motives such as the desire of spouse/partner for children were of secondary importance and pressure from family and friends was of little importance.
- Patients' expectations of having a baby were generally substantially higher than the estimates provided to them by the clinics. This factor, as well as the fact that patients want to know their probability of success, points to a need for more explicit, formal systems for informing patients. An example of such a system is the computer model projection that one hospital prints out for each patient.
- Fertility clinic patients were generally drawn from high education and income groups. They were twice as likely to have incomes of \$50 000 per year or more compared to all Canadian families.
- Higher level reproductive technologies were usually used in the appropriate circumstances (e.g., IVF for tubal problems), but not in all cases. From the patient's perspective, clinics appear to use these technologies in a wide variety of cases, sometimes when a lesser technology might be a more appropriate first step in treatment.
- The costs of fertility treatments were high, particularly for IVF, with patients spending many thousands of dollars directly on clinic costs, drugs, and travel, and indirectly as a result of time lost from work. The total costs for IVF patients in Ontario were dramatically lower (about \$5 300) than the total costs for IVF patients from other provinces (about \$9 000).
- Patients' assessments of information provided by clinics varied, with some topics reported to be well covered by clinics, but the kind of information provided by clinics in many areas was rated low.
- Patients were generally satisfied with the way decisions were made regarding their treatment: most decisions were made jointly by patients, their partners, and physicians; only a small

proportion of patients reported unilateral decision making by physicians.

- Patients' assessments of the quality of service provided by clinics varied, with some clinics being rated as excellent and others as performing poorly. But most patients reported that they would recommend both fertility treatments and their specific clinics to a friend.
- The information and services that were most important to patients were often not those that the clinic provided most effectively. Many clinics provided high quality information, but often it was not information on aspects that patients wanted most. For example, patients were very interested in their chance of having a baby, but the kind of information provided in this regard varied a great deal.
- There is, generally, a need for more counselling, especially after the conclusion of treatments. By counselling, respondents meant primarily improved consultation with the physician and nurse — counselling by social workers or psychologists was rated as less important to them.
- Clinics generally varied widely in the quality of the service they offered. Many patients reported very satisfactory experiences, while others (a minority) reported very poor treatment both in technical terms and in terms of meeting their needs on aspects such as comfort and dignity. These variations did not follow clear trends or patterns by institutional type. Different institutional types (teaching or non-teaching hospitals/clinics) ended up with ratings of best, average, and worst on a composite scale that evaluated the facilities participating in this study.
- Most patients reported that the treatments had a wide range of positive effects, for example, on their self-esteem and their relations with their partners, even though a wide range of difficulties such as stress, physical difficulties, and financial problems was noted.
- Patients were generally intent on continuing fertility treatments until they succeeded in having a child or until they could no longer continue financially and emotionally. Many patients pursued adoption while undertaking treatment.
- Public funding in Ontario reduced the cost of fertility treatments for patients but did not result in significantly greater access to treatment by lower income groups.
- Information, counselling, decision making, and informed consent procedures in clinics were important factors predicting patient satisfaction. Those clinics performing well in these areas also

performed well on the outcome measure of the success of treatments (pregnancy or the birth of a baby). The closeness of match of clinic information and service priorities to patient priorities was found to be a particularly significant factor in both patient satisfaction and the success of treatment.

Overall, the survey results suggest that Canadian fertility clinics provide a service that is regarded as extremely important and valuable by their clients. It could be concluded from these results that strong consumer demand for treatment in fertility clinics will continue. At the same time, the results show a clear need for improved standards, particularly in the areas of information, counselling, and decision making. Patients' concerns regarding a lack of information are particularly important, since it is difficult to argue that patients have provided informed consent when their valid demands for information are underserved.

It is interesting that the results of this one-time national survey correspond very closely with results of Wright's in-depth, longitudinal study of patients in one major fertility clinic.³² He also examined the need for counselling, information, and participation in decision making, and produced remarkably similar findings.³³ The similarity between the findings of these studies (with their complementary methodological strengths and weaknesses) points toward a high degree of validity for these conclusions.

Appendix 1. Questionnaire

Royal Commission on New Reproductive Technologies Survey of Patients of Canadian Fertility Clinics

Introduction: The Government of Canada has directed the Royal Commission on New Reproductive Technologies to examine and make recommendations on a wide range of issues relating to reproductive technologies. The purpose of this survey is to enable the Royal Commission to understand the experiences and opinions of patients of Canadian fertility clinics. This survey is a key source of information for the Commission and a necessary component in its deliberations about the advice it will offer to the government. For that reason, we hope you will take the time to assist us by completing this survey.

The survey examines your experiences with the clinic noted at the right. Throughout, the survey refers to it as *this fertility clinic*, or *the clinic*. Please give your answers in reference to the clinic noted here.

Survey topics cover almost all aspects of clinic experiences, including: the kind and completeness of information provided before and during treatment; treatment experiences; decision making and outcomes; and your satisfaction. A number of questions which are asked are similar to those asked in the national Census — about education, employment, income, etc. The survey also provides an opportunity for you to express your own suggestions to the Commission regarding fertility clinics, or on broader issues related to new reproductive technologies.

Confidentiality: The survey is strictly voluntary and completely confidential. There are no personal identifiers on the questionnaire, and you are not asked to place your name on the questionnaire. Only statistical results will be included in our report — your personal answers will never be revealed to your clinic or to anyone at the clinic, or be known to anyone outside of the Commission research offices. All questionnaires will be destroyed at the conclusion of the survey.

Who Should Complete the Survey: The questions should be answered by the *patient*, and can be completed in cooperation with the spouse/partner. One page in the questionnaire is to be completed separately by the patient and by the spouse/partner respectively. As well, the comments space at the end of the questionnaire can be used by either or both the patient and spouse/partner. If you do not have a spouse/partner, you should answer the questionnaire alone.

How to Answer the Questions: First, look through the entire questionnaire, to see what topics are included. Then begin to answer the questions, starting on page 1. Most questions can be answered by checking the box or circling the number which best describes your answer or opinion, based on your experiences. For some questions you need to write in an answer in your own words. *Where you write in an answer, please **PRINT CLEARLY**.* If you feel a question does not apply to you, write in “NA” for your answer. If you are not sure about an answer, please write in “don’t know.” If the answer choices we offer do not apply and you have another answer, feel free to write it in. If you feel that any question is too sensitive or you do not want to answer it — feel free to leave it blank. If you have any questions about the survey, how to complete it or any related matter, please telephone our survey hotline, collect, at (416) 467-8430.

When You Have Completed the Survey: Seal it in the envelope provided (no postage is needed), and return it to the address indicated (Fertility Clinic Patient Survey, Royal Commission Survey Office, 2318 Danforth Avenue, 2nd Floor, Toronto, Ontario, M4C 9Z9).

**COMPLETION OF THIS SURVEY IS STRICTLY VOLUNTARY
AND CONFIDENTIAL**

Ce questionnaire est aussi disponible en français. Si vous désirez en obtenir un exemplaire, composez le (416) 467-8242, à frais virés.

A. Background Information. These questions are about you before you came to this fertility clinic.

A.1 When did you think you/your spouse/partner might have a fertility problem? (PLEASE ESTIMATE "YEAR" IF YOU CANNOT REMEMBER EXACT MONTH AND YEAR) _____ (MONTH) _____ (YEAR)

A.2 At that time, for how many years had you been trying to have a child? _____ (YEARS)

A.3 Did you and your spouse/partner have any children at that time?
No ---> (GO TO QUESTION A.6)
Yes

A.4 (IF YES) At that time, how many children did you and your spouse/partner have in each category (a) to (e), and what were their ages? (INDICATE NUMBER AND AGES OF ALL CHILDREN)

	Number of children	Their age(s)
(a) Children born to you and your spouse/partner	_____	_____
(b) Children born to you in a previous relationship	_____	_____
(c) Children born to your spouse/partner in a previous relationship	_____	_____
(d) Children which you and/or your spouse/partner adopted	_____	_____
(e) Other children	_____	_____

A.5 How many of the above children (if any) were born to you through the use of fertility treatments? _____

A.6 How many years had you and your spouse/partner been living together when you became aware of the fertility problem?
_____ (YEARS)

A.7 When did you first seek an explanation (diagnosis) for the fertility problem? _____ (MONTH) _____ (YEAR)

A.8 Was this first diagnosis provided by this fertility clinic or by a doctor who works with this clinic?

Yes ---> (GO TO QUESTION A.11, NEXT PAGE)

No

A.9 Who did you see about your fertility problem before your first visit to this fertility clinic or to a doctor who works with this clinic? (CHECK ALL THAT APPLY)

Family physician/general practitioner

Gynaecologist

Fertility specialist

Urologist

Endocrinologist

Some other type of specialist (SPECIFY WHAT TYPE): _____

Another fertility clinic

Some other source (SPECIFY WHAT TYPE): _____

A.10 Which (if any) of the following fertility-related drug treatments, surgery or other treatments did you receive before your first visit to this fertility clinic? (CHECK ALL THAT APPLY)

Fertility drug therapy (for example, to increase ovulation)

Artificial insemination with spouse/partner sperm

Artificial insemination with donor sperm

Surgery (PLEASE SPECIFY): _____

Other (PLEASE SPECIFY): _____

None of the above

A.11 Did you consider adoption before going to this fertility clinic? (CHECK ONE)

Yes, applied for adoption and adopted a child

Yes, applied for adoption but were not approved to receive a child

Yes, applied for adoption and still awaiting approval or waiting for a child

Yes, considered adoption but did not apply

No, did not consider adoption at all
Other (PLEASE SPECIFY): _____

A.12 Who suggested that you go to this fertility clinic? (CHECK ALL THAT APPLY)

- Referred yourself after reading, etc.
- Spouse/partner
- Other family members
- Friends
- Family physician/general practitioner
- Gynaecologist
- Fertility specialist
- Some other type of specialist (SPECIFY WHAT TYPE): _____
- Another fertility clinic
- Some other source (SPECIFY WHAT SOURCE): _____

A.13 What (if anything) did you do to gather information before first contacting this fertility clinic? (CHECK ALL THAT APPLY)

- Read general literature, self-help books
- Read literature from this or another fertility clinic
- Watched video on fertility topics
- Discussed with past or current patients at this clinic or another fertility clinic
- Discussed with a support group
- Discussed with family physician/general practitioner
- Discussed with gynaecologist
- Other (PLEASE SPECIFY): _____
- None of the above

A.14 How important were each of the following in your decision to go to a fertility clinic? (CIRCLE THE NUMBER FOR (a) TO (g) THAT BEST DESCRIBES HOW IMPORTANT EACH WAS TO YOU)

	Not important		Somewhat important		Very important	
(a) Your own desire for children	1	2	3	4	5	
(b) Your spouse/partner's desire for children	1	2	3	4	5	
(c) Family members' pressure for you to have children	1	2	3	4	5	

	Not important		Somewhat important		Very important
(d) Family members' support for your desire to have children	1	2	3	4	5
(e) Friends' pressure for you to have children	1	2	3	4	5
(f) Friends' support for your desire to have children	1	2	3	4	5
(g) Other factor (PLEASE DESCRIBE): _____ _____	1	2	3	4	5

A.15 When did you first contact this fertility clinic? _____ (MONTH)
_____ (YEAR)

A.16 When did you have your first interview or appointment with this fertility clinic? _____ (MONTH) _____ (YEAR)

B. Treatment at this Clinic. These questions are about the treatment you received at this clinic.

B.1 When did you begin treatment at this clinic? _____ (MONTH)
_____ (YEAR)

B.2 What was the clinic's/doctor's explanation (diagnosis) of the fertility problem at the time you began treatment? (CHECK ALL THAT APPLY)

Problem with egg production (ovulation)

Sperm problem(s)

Endometriosis

Problem(s) with (fallopian) tubes

Problem(s) with menstruation

Problem(s) with uterus

A (cervical) mucus problem

No known problem (unexplainable)

Other (PLEASE SPECIFY): _____

B.3 Which of the following were described by the clinic/doctor as possible treatments for you? (CHECK ALL THAT APPLY)

- | | |
|--|--|
| Fertility drugs | Sperm wash/Intrauterine insemination |
| Artificial insemination with partner's sperm | Some other treatment (PLEASE SPECIFY): _____ |
| Artificial insemination with donor sperm | None of the above |
| In vitro fertilization | |

B.4 Which treatments were recommended by the clinic/doctor? (CHECK ALL THAT APPLY)

- | | |
|--|--|
| Fertility drugs | Sperm wash/Intrauterine insemination |
| Artificial insemination with partner's sperm | Some other treatment (PLEASE SPECIFY): _____ |
| Artificial insemination with donor sperm | None of the above |
| In vitro fertilization | |

B.5 What treatment(s) did you receive at this clinic? (CHECK ALL THAT APPLY AND INDICATE THE NUMBER OF MONTHS OR CYCLES)

- | | |
|--|----------------------------|
| Fertility drugs -----> | # of months: _____ |
| Artificial insemination with partner's sperm -----> | # of months: _____ |
| Artificial insemination with donor sperm -----> | # of months: _____ |
| In vitro fertilization -----> | # of cycles started: _____ |
| Sperm wash/Intrauterine insemination-> | # of months: _____ |
| Some other treatment (PLEASE SPECIFY):
_____ -----> | # of months: _____ |

B.6 When you began treatment, how did the clinic staff describe the chances for successful treatment? (CHECK ALL THAT APPLY)

Number between 1% and 100%

- | | |
|--|--|
| In terms of chance of pregnancy -----> | What approximate percentage of chance? _____ % |
| In terms of chance of having a baby -----> | What approximate percentage of chance? _____ % |

No estimate was given of chance of success

Other (PLEASE SPECIFY):

B.7 Is all your treatment at this clinic now ended? (CHECK ONE)

No, still receiving treatment

Yes, treatment was ended -----> (GO TO QUESTION B.9)

Treatment was stopped, but will continue
at a later date -----> (GO TO QUESTION B.9)

Not decided

B.8 How many more months/cycles are you planning to continue with
this treatment at this clinic?

_____ (MONTHS) _____ (CYCLES) Not certain

B.9 How many more months/cycles are you planning to continue with
any fertility treatment?

_____ (MONTHS) _____ (CYCLES) Not certain

CONSENT FORMS

B.10 Did the staff at this clinic: (CHECK ONE BOX FOR EACH OF (a) TO
(h))

YES NO

- (a) Ask you to sign any consent forms? ---> (IF
NO, GO TO QUESTION B.12)
- (b) Ask you to sign written consent forms before
any treatment began?
- (c) Fully explain the purpose of the consent
forms?
- (d) Provide you with adequate time to ask
questions about the consent forms?
- (e) Indicate that your consent could be
withdrawn at any time if you wished, without
affecting your future care?
- (f) Give you (and your spouse/partner) enough
privacy to discuss the consent forms before
they had to be signed?

- (g) Give you (and your spouse/partner) enough time to discuss the consent forms before they had to be signed?
- (h) Give you copies of the signed consent forms to keep?

B.11 Were the consent forms easy or difficult to understand? (PLEASE CIRCLE THE NUMBER BETWEEN 1 AND 5 WHICH BEST DESCRIBES HOW EASY THESE WERE FOR YOU TO UNDERSTAND)

Easy to understand					Difficult to understand
1	2	3	4	5	

COSTS

B.12 Please estimate your personal total out-of-pocket costs (if any) and indirect costs, for the treatment(s) received at this clinic. (PLEASE INCLUDE ALL COSTS, OR COSTS TO DATE, INCLUDING COSTS OF TRAVEL, ACCOMMODATION, LOST WORK TIME, ETC.)

\$ _____ paid directly to the clinic
 \$ _____ other treatment costs (e.g., fertility drugs)
 \$ _____ other direct costs (e.g., travel, accommodation)
 \$ _____ indirect costs (e.g., lost work time)

B.13 Were (or will) any of these costs be paid for by any private or employer-paid health insurance (other than provincial health insurance)?

Yes ---> How much was (will be) paid? \$ _____

No, have private or employer health insurance, but it did not/does not cover the treatments

No, do not have private or employer health insurance

C. After Treatment. These questions are only for patients who have ended their treatment at this clinic. **If you are still receiving treatment at this clinic, please go to Section D.**

C.1 When was the treatment ended or stopped?

_____ (MONTH) _____ (YEAR)

C.2 How was the treatment ended or stopped? (CHECK ONE)

At the end of a cycle -----> (GO TO QUESTION C.5)

The treatment was stopped

by the clinic -----> (GO TO QUESTION C.5)

The treatment was stopped by the patient

Other (PLEASE SPECIFY): _____

C.3 (IF YOU ENDED THE TREATMENT) Did you tell the clinic that you were ending the treatment? _____ Yes _____ No

C.4 (IF YOU ENDED THE TREATMENT) Why did you end the treatment? (CHECK ALL THAT APPLY)

Pregnancy

Adopted a child

Psychological/emotional stress

Physical difficulties (e.g., fertility drug effects)

Costs (too expensive)

Other (PLEASE SPECIFY): _____

C.5 Was the treatment successful (as measured by pregnancy/having a baby or by success in other ways)? (CHECK ONE)

Yes, have had a baby

Yes, pregnant now

Neither of the above

Other success (PLEASE DESCRIBE): _____

C.6 Was follow-up counselling provided regarding any of the following? (CHECK ALL THAT APPLY)

Pregnancy/birth

Adoption as an option

Other fertility treatment choices

Dealing with emotional effects of treatment

No follow-up/counselling was offered

No follow-up/counselling was desired

C.7 Did you have a "last" or "exit" interview with clinic staff when treatment ended? _____ Yes _____ No

C.8 How likely is it that you will try fertility treatments in the future?
(CHECK ONE)

Very likely

Likely

Uncertain

Unlikely

Very unlikely ----->

Why will you not try fertility
treatments in the future?

PLEASE GO TO SECTION D AND CONTINUE WITH THE REST OF THE QUESTIONNAIRE

D. **Information and Decision Making.** These questions are about the information you received at this fertility clinic, and how decisions are/were made.

D.1 Please circle the number that best describes your opinion of the quality of the information (both verbal or written) this clinic gave you for each of (a) to (v). (IF ANY TYPE OF INFORMATION WAS NOT GIVEN, PLEASE CHECK THE "NOT GIVEN" BOX)

Information about:	Quality of information given:				
	Not given	Poor	Adequate	Excellent	
(a) Specific information about your fertility problem		1	2	3	4 5
(b) Adoption as an alternative		1	2	3	4 5
(c) Treatment alternatives, choices (e.g., IVF, artificial insemination, sperm wash and IUI, fertility drugs)		1	2	3	4 5
(d) Live birth rates of this clinic		1	2	3	4 5
(e) Live birth rates of specific procedures/treatments		1	2	3	4 5
(f) Your personal chances of having a baby		1	2	3	4 5
(g) Information about the experience/qualifications of clinic staff		1	2	3	4 5

Information about:	Not given	Quality of information given:			
		Poor	Adequate	Excellent	
(h) The short-term/immediate effects of procedures/tests and fertility drugs		1	2	3	4 5
(i) The longer-term effects of procedures/tests and fertility drugs		1	2	3	4 5
(j) What you had to do to make the treatments successful (lifestyle choices, e.g., smoking, intercourse)		1	2	3	4 5
(k) Specifics of risk to a child produced as a result of treatment		1	2	3	4 5
(l) Chance of a multiple pregnancy (twins, triplets)		1	2	3	4 5
(m) Direct total financial costs of treatment (what you pay directly to the clinic and for out-of-pocket expenses such as travel)		1	2	3	4 5
(n) Indirect financial costs (such as lost time from work)		1	2	3	4 5
(o) Demands of treatment on your time		1	2	3	4 5
(p) Physical demands of treatment (pain, exhaustion)		1	2	3	4 5
(q) Emotional demands of treatment (stress, depression)		1	2	3	4 5
(r) Demands on your relationship with your spouse/partner		1	2	3	4 5
(s) Use/handling of extra eggs after the end of treatment		1	2	3	4 5
(t) Use/handling of extra semen after the end of treatment		1	2	3	4 5
(u) Use/handling of extra embryos after the end of treatment		1	2	3	4 5
(v) Consent forms you would be asked to sign		1	2	3	4 5

D.2 Considering all of the possible types of information identified above as (a) to (v), which types of information do you feel it is particularly important for a patient to have? (CIRCLE AS MANY AS YOU FEEL ARE IMPORTANT)

a b c d e f g h i j k
l m n o p q r s t u v

D.3 Please circle the number that best describes your opinion of your experience at this clinic for each of (a) to (l). (IF ANY OF THESE WERE NOT GIVEN AT ALL, PLEASE CHECK THE “NOT GIVEN” BOX)

Clinic Process		Not given	Poor	Adequate	Excellent		
(a)	Treatment(s) for yourself		1	2	3	4	5
(b)	Treatment(s) for your spouse/partner		1	2	3	4	5
(c)	Information sessions with clinic staff		1	2	3	4	5
(d)	Written information (brochures or other written materials)		1	2	3	4	5
(e)	Videotaped information of material		1	2	3	4	5
(f)	Counselling for yourself		1	2	3	4	5
(g)	Counselling for your spouse/partner		1	2	3	4	5
(h)	Opportunities to think over treatment information before making decisions		1	2	3	4	5
(i)	Opportunities to discuss decisions with spouse/partner		1	2	3	4	5
(j)	Opportunities to discuss treatment decisions with clinic staff, raise questions and have them answered		1	2	3	4	5
(k)	Opportunities to discuss treatment decisions with other patients or support group		1	2	3	4	5

Clinic Process	Not given	Poor	Adequate	Excellent		
(l) Opportunities to discuss treatment decisions with someone not directly related to the clinic program (e.g., a hospital social worker or counsellor)		1	2	3	4	5

D.4 Considering the above aspects of clinic process identified as (a) to (l), which aspects do you feel are/were particularly important to you as a patient? (CIRCLE AS MANY AS YOU FEEL ARE IMPORTANT)

a b c d e f g h i j k l

D.5 Please circle the number that best describes your opinion of your experiences at this clinic for each of (a) to (h).

		Poor	Adequate	Excellent		
(a)	Time spent waiting at the clinic (for appointments to see staff, to get test results, information)	1	2	3	4	5
(b)	Continuity and consistency of clinic service (consistent information, always talking to the same staff, regular follow-up, etc.)	1	2	3	4	5
(c)	Ongoing information the clinic provided about your treatment and progress	1	2	3	4	5
(d)	Comprehensiveness of clinic facilities (all tests, etc. in one location)	1	2	3	4	5
(e)	Comfort/pleasantness of the clinic facilities	1	2	3	4	5
(f)	Clinic staff support and understanding of your needs as a person	1	2	3	4	5
(g)	Respect for your privacy	1	2	3	4	5
(h)	Respect for your confidentiality	1	2	3	4	5

D.6 Of the above aspects of the clinic process (a) to (h), which ones do you feel are/were particularly important to you as a patient? (CIRCLE AS MANY AS YOU FEEL ARE IMPORTANT)

a b c d e f g h

D.7 At the start of treatment, how confident were you that the treatment would be successful in enabling you to have a baby? (CIRCLE THE NUMBER BETWEEN 1 AND 5 WHICH BEST DESCRIBES HOW YOU FELT AT THE TIME)

Very confident			Uncertain		Not confident at all
1	2	3	4	5	

D.8 How often did/does your spouse/partner go to this clinic with you? (CHECK ONE)

Always	Sometimes	Rarely	Never
--------	-----------	--------	-------

D.9 Who made the decisions regarding the following? (CHECK ONE FOR EACH OF (a) TO (c))

	You/your spouse/partner	You/your spouse/partner with doctor	Doctor
(a) What your treatment options were/are			
(b) Which treatment(s) to have			
(c) When to continue/stop treatment(s)			

D.10 Do you feel that the clinic provides/provided the right amount of each of the following to meet your needs? (CHECK ONE FOR EACH OF (a) TO (f))

	Not enough	Just right	Too much
(a) Opportunities for <u>you</u> to participate in decisions			
(b) Opportunities for <u>your spouse/partner</u> to participate in decisions			
(c) Information about all aspects of treatment			
(d) Counselling <u>before</u> treatment began			
(e) Counselling <u>during</u> treatment			
(f) Counselling <u>after</u> treatment			

D.11 Did you apply/have you applied for adoption after starting treatment at this clinic? (CHECK ONE)

- Yes, applied for adoption, but were not approved to receive a child
- Yes, applied for adoption and still awaiting approval or waiting for a child
- Considered adoption but did not apply
- No, did not consider or apply
- Other (PLEASE SPECIFY): _____

D.12 What other approaches (if any) are you considering or will you consider in the future? (CHECK ALL THAT APPLY)

- No further fertility treatments at all
- Continue with current treatment at this clinic
- Fertility treatments with a private practitioner
- Treatment by another fertility clinic
- Other treatments with a general practitioner
- Other treatments with a specialist
- (SPECIFY TYPE OF TREATMENT): _____
- Other treatments outside Canada
- (SPECIFY TYPE OF TREATMENT): _____
- Pursuing adoption now
- Will pursue adoption in the future
- Surrogacy

D.13 Would you recommend fertility treatments to a friend in your situation?

- Yes No

D.14 Would you recommend this particular fertility clinic to a friend?

- Yes No

E. Effects of Treatment on the Patient and Demographics. These questions are about the effects of the treatments on you, and social-economic characteristics.

E.1 How has the clinic treatment affected each of the following for you?
(PLEASE CIRCLE ONE ANSWER FOR EACH OF (a) TO (f))

	Positive effect		No effect	Negative effect	
(a) Feelings about yourself	1	2	3	4	5
(b) Feelings of control over your life	1	2	3	4	5
(c) Feelings about your role in the treatment	1	2	3	4	5
(d) Your feelings of privacy/dignity	1	2	3	4	5
(e) Your relationship with your spouse/partner	1	2	3	4	5
(f) Your life overall	1	2	3	4	5

E.2 How difficult were the following aspects of treatment for you?
(PLEASE CIRCLE ONE ANSWER FOR EACH OF (a) TO (g))

	Not difficult		Somewhat difficult	Very difficult	
(a) Emotional stress for <u>you</u>	1	2	3	4	5
(b) Physical demands for <u>you</u>	1	2	3	4	5
(c) Emotional stress after <u>your</u> <u>spouse/partner</u>	1	2	3	4	5
(d) Physical demands for <u>your</u> <u>spouse/partner</u>	1	2	3	4	5
(e) Direct economic costs (to you/your spouse/partner)	1	2	3	4	5
(f) Indirect economic costs (such as lost work time)	1	2	3	4	5
(g) Stress of failures (from unsuccessful efforts)	1	2	3	4	5

E.3 In what year were you born? _____

E.4 What is your sex? Female Male

E.5 What is the language you first learned at home in childhood?
(CHECK ONE)

English French Other (PLEASE SPECIFY): _____

E.6 What is the highest level of education you have achieved?

Grade: _____ or Community college/Technical school

University/College ---> What degree (if any)?

Graduate school -----> What degree (if any)?

Other (PLEASE SPECIFY): _____

- E.7 Approximately how many weeks in 1990 were you: Employed full-time? _____ (# OF WEEKS) (INDICATE "0" IF NONE)
Employed part-time? _____ (# OF WEEKS)
- E.8 Approximately how many weeks in 1991 were you: Employed full-time? _____ (# OF WEEKS) (INDICATE "0" IF NONE)
Employed part-time? _____ (# OF WEEKS)
- E.9 We would like some information about your present or most recent job. What kind of work do (or did) you do at your job? (FOR EXAMPLE, MEDICAL LAB TECHNICIAN, ACCOUNTING CLERK, SALESPERSON, SECONDARY SCHOOL TEACHER, CONSTRUCTION WORKER, ETC.)

F. Effects of Treatment on Spouse/Partner and Demographics. This page is intended for completion by the spouse/partner. If no spouse/partner, check the box here ---> ☐ and go to the next page. If the spouse/partner is not available to complete this page, the patient should complete Questions F.3 to F.9.

F.1 How has the clinic treatment affected each of the following for you? (PLEASE CIRCLE ONE ANSWER FOR EACH OF (a) TO (f))

	Positive effective		No effect	Negative effect	
(a) Feelings about yourself	1	2	3	4	5
(b) Feelings of control over your life	1	2	3	4	5
(c) Feelings about your role in the treatment	1	2	3	4	5
(d) Your feelings of privacy/dignity	1	2	3	4	5
(e) Your relationship with your spouse/partner	1	2	3	4	5
(f) Your life overall	1	2	3	4	5

F.2 How difficult were the following aspects of treatment for you?
(PLEASE CIRCLE ONE ANSWER FOR EACH OF (a) TO (g))

	Not difficult		Somewhat difficult	Very difficult	
(a) Emotional stress for <u>you</u>	1	2	3	4	5
(b) Physical demands for <u>you</u>	1	2	3	4	5
(c) Emotional stress after <u>your</u> <u>spouse/partner</u>	1	2	3	4	5
(d) Physical demands for <u>your</u> <u>spouse/partner</u>	1	2	3	4	5
(e) Direct economic costs (to you/your spouse/partner)	1	2	3	4	5
(f) Indirect economic costs (such as lost work time)	1	2	3	4	5
(g) Stress of failures (from unsuccessful efforts)	1	2	3	4	5

F.3 In what year were you born? _____

F.4 What is your sex? Female Male

F.5 What is the language you first learned at home in childhood?
(CHECK ONE)

English French Other (PLEASE SPECIFY): _____

F.6 What is the highest level of education you have achieved?

Grade: _____ or Community college/Technical school
University/College ---> What degree (if any)?

Graduate school -----> What degree (if any)?

Other (PLEASE SPECIFY): _____

F.7 Approximately how many weeks in 1990 were you: Employed full-
time? _____ (# OF WEEKS) (INDICATE "0" IF NONE)
Employed part-time? _____ (# OF WEEKS)

F.8 Approximately how many weeks in 1991 were you: Employed full-time? _____ (# OF WEEKS) (INDICATE "0" IF NONE)
Employed part-time? _____ (# OF WEEKS)

F.9 We would like some information about your present or most recent job. What kind of work do (or did) you do at your job? (FOR EXAMPLE, MEDICAL LAB TECHNICIAN, ACCOUNTING CLERK, SALESPERSON, SECONDARY SCHOOL TEACHER, CONSTRUCTION WORKER, ETC.)

G. Household Characteristics. In addition to the household information already provided, the Commission wishes to know about household income, so that it can better assess the significance of cost as a factor in access to fertility treatments.

G.1 What was your household's approximate combined total annual income in 1991 before deductions? (CHECK ONE)

- | | |
|----------------------|----------------------|
| Under \$20 000 | \$40 000 to \$49 000 |
| \$20 000 to \$29 000 | \$50 000 to \$59 000 |
| \$30 000 to \$39 000 | Over \$60 000 |

H. **Comments** (for both patient and spouse/partner)

H.1 What other comments (if any) do you have for the Commission on the topic of fertility clinics, fertility treatment or related issues? If you have attended other fertility clinics or treatments and wish to comment on your experiences, please do so here (feel free to attach additional sheets if necessary).

I. **Survey Completion**

I.1 Who completed this survey? (CHECK ALL THAT APPLY)

- Patient only
Patient and spouse/partner together
Spouse/partner only
Other (PLEASE SPECIFY): _____

I.2 Did you consult with the clinic, or clinic staff in any way about completion of the survey?

Yes No

I.3 Did clinic staff make any suggestions about how you should answer the survey questions which evaluated the clinic or its services or information?

Yes No

THANK YOU VERY MUCH FOR YOUR TIME. PLEASE MAKE SURE THAT YOU HAVE FOLLOWED ALL INSTRUCTIONS, AND THEN RETURN THE QUESTIONNAIRE IN THE POSTAGE-PAID ENVELOPE PROVIDED.

VOLUNTARY: THIS SEPARATE SHEET IS TO BE RETURNED ONLY IF THE PATIENT/COUPLE WISHES. YOU MAY CHOOSE TO SEND THIS SHEET BACK ALONG WITH THE QUESTIONNAIRE OR IN A SEPARATE ENVELOPE (IN WHICH CASE YOU WOULD PROVIDE THE POSTAGE). IF YOU DO NOT WANT TO COMPLETE THIS SHEET, YOU MAY STILL ASK FOR A COPY OF THE REPORT BY TELEPHONING THE ROYAL COMMISSION AT 1-800-668-7060.

Would you like to receive a summary of the Commission's report on this survey?

Yes ---> (Please complete the address/information form below, for purposes of the Commission's mailing only, or call the 1-800 number listed above)

No

ADDRESS/INFORMATION FORM

Last name: _____ First name: _____ Initial: _____

Street and number: _____ Apartment/Unit: _____

City: _____ Province: _____ Postal code: _____

Area code: _____ Telephone number: _____

Appendix 2. Notes on Methodology

Survey Start-up: Securing Clinic Participation

While the survey start-up was highly successful and most clinics participated, there were some difficulties. There were delays at some clinics for various reasons (e.g., key staff were on holidays, medical directors went away with the survey package, courier shipments were delivered to the hospital but were never seen, and doctors had to consult with colleagues about participating).

Examples of delaying factors at specific clinics included:

- Hôpital de Chicoutimi required a special letter seeking approval of the president of the hospital;

- at the Health Sciences Centre, University of Manitoba a delay was needed to enable a comprehensive ethics committee review prior to participation;
- at the University Hospital (London) there were delays in starting as the University of Western Ontario required the survey to be reviewed by a full ethics committee prior to participation; and
- communication with the University Hospital (Vancouver) where there was confusion over the administrative locus of the clinic.

Several clinics either refused to participate, were impossible to contact, could not participate within the study time frame, or were not enlisted in the survey. These were as follows:

- St. Michael's Hospital (Toronto) was not operating the fertility clinic at the time of the survey because of financial difficulties at the hospital;
- at the Institut de Médecin de la Reproduction (Montreal) the nurse administrator reported that the director did not wish to participate (no reason was given);
- the C.A.R.E. Centre (Mississauga) refused to participate; it required control over patient survey returns as a condition of participation;
- the Centre hospitalier at the University of Laval (Quebec City) refused to participate, saying that the survey's concerns with patient information were irrelevant;
- at the Ottawa General Hospital the nursing staff did not wish to participate; and
- the centre hospitalier at Sherbrooke University in Quebec indicated that an ethics review was required, but it could not start until September, after the proposed study completion date.

Sampling

The rationale for the sampling strategy was based on several factors that made the mailings unpredictable, especially with regard to timing. The number of patients was uncertain because of the methods of record keeping. In many cases, the number of patients reported by clinics dropped dramatically from the time initial contact was made with the clinic, the questionnaire packages were shipped to the clinic, and the actual mailings. Generally, clinics found it extremely difficult to estimate the actual numbers of patients, since most keep counts of visits or cycles but not patients per se. Some existing counts (see companion Survey of Canadian Fertility Clinics) include double counting of patients in different treatments (for example, a clinic might report that there were 300 patients

in IVF and 300 in AI in 1991, but the total number of patients might be only 500).

Some clinics agreed to mail questionnaires to those on their patient list, but there were delays in placing the survey in the mail (even the best cases took weeks before the surveys were actually mailed). In addition, a number of the survey envelopes were incorrectly addressed because of typing errors on the labels or out-of-date addresses, so the effective mailing had to be reduced by a factor. (Normally the number of poor addresses in a mailing is about three times the number actually returned to sender.)

Finally, we expected that some clinics would include pre-1991 patients in the mailings, requiring some returns to be disqualified and the initial sample size to be adjusted. The questionnaire responses confirm that this was a valid assumption.

As a result of all these factors, there was an effective mailing of approximately 3 450 survey questionnaires to fertility clinic patients.

Weighting of Data

Several weights (but not statistical tests of significance) were applied in estimating the figures for this report to ensure the representativeness of the survey estimates:

1. To offset initial sampling probabilities in cases where sampling was done within clinics, the responses were weighted by the ratio of the estimated population to the number of patients sampled. For example, if the clinic had 400 patients and 100 were sampled, a weight of $(400/100 =) 4$ was applied to each responding case.
2. To account for survey non-response, a weight representing the ratio of cases sampled was applied to those responding. For example, if 100 cases were sampled and 50 responded, the weight applied was $(100/50 =) 2$.
3. To offset a slight tendency for about 5% over-response by "successful" patients who had concluded treatment and about 5% under-response by unsuccessful patients who had concluded their treatment, weights of 0.95 and 1.05 respectively were applied for patients reporting their treatment concluded successfully or unsuccessfully.

Data Quality

Reporting difficulties found on the questionnaire were as follows:

Section A

- A number of respondents were aware of their fertility problem for many years before the beginning of their relationship with their spouse/partner. There were many reasons for infertility in these cases; for example, tubal ligation, genetic causes, and repro-

ductive disease. These instances were captured in the data with a special code.

- The few single women respondents, without a spouse/partner, who had difficulty with question A.1 were captured with a special code.
- Because in some cases a length of time elapsed between the discovery of a fertility problem and 1991 (the year used by the survey sample as a treatment basis), a number of biological or adopted children were not captured by question A.4. Therefore, consistency of patients' responses to a number of questions (which reflected presence or absence of children) was reviewed. Biological or adopted children not accurately captured by question A.4 were coded separately.

Section B

- In question B.5, many combinations of treatment were reported by the respondents and we suspected some overlap. For instance, AIH might be indicated as being received for the same number of months as sperm wash/IUI, or fertility drugs might be reported in cycles that corresponded with the number of IVF cycles. This led us to suspect that some respondents were referring to a single procedure (i.e., IVF cycles with fertility drugs or sperm wash/IUI with the partner's sperm). (Sperm wash/IUI with a donor's sperm is also a possibility, although certainly, in our observation, not frequent.) These instances of respondents reporting fertility drugs and all types of AI in cycles instead of months were also captured in the coding.

Section D

- All answers to question D.11 were checked against the answers to A.11 to ensure consistency of response regarding adoption considerations before and after treatment began.
- In the second category of question D.12, which reads, "Continue with current treatment at this clinic," we noted that respondents checked this box if they planned to return to try to have another baby (i.e., they had already had a successful pregnancy at the clinic).
- The ninth category of question D.12 should have read, "May pursue adoption in the future." In the same question, "Other (specify)" would have captured other options respondents might wish to pursue in the future.

Non-Response Bias

Analysis of non-response substudy data indicated that there were only minor differences between those responding to the survey on the basis of an initial mail-out, those responding after a reminder, and those indicating they did not wish to respond. Generally, those not wishing to respond cited survey-related reasons for not responding (e.g., the survey was too long or too detailed, or they were too busy).

As for general satisfaction, non-respondents were — like respondents — overwhelmingly likely to report that they were satisfied with the clinic services and that they would generally recommend the clinic or fertility treatments to a friend in the same situation. Non-respondents differed from respondents in satisfaction, but not substantially; for example, 93% of non-respondents indicated that they would recommend fertility treatments to a friend, compared to 85% of respondents (non-respondents were more satisfied). In contrast, one subgroup of non-respondents cited the fact that their treatments had not been successful as a reason for not responding to the survey. This factor was cited as frequently as the length of the survey as a reason for not responding.

Appendix 3. Supplementary Statistical Tables

Table 3A. Means for Various Variables				
	Treatment type			
	IVF	AIH	AID	Other treatments
Total amount of information received	19.21	15.61	15.65	13.84
Rating of time given to think over decisions	2.99	2.83	2.97	2.76
Number of types of counselling/support given	2.70	1.76	1.56	1.02
Number of fertility consultations prior to clinic	1.72	1.62	1.45	1.32
Number of fertility treatments prior to clinic	1.42	1.09	0.59	0.77
Number of types of information gathered before clinic	2.13	1.90	1.72	1.63
Husband/wife motive for children	7.48	7.52	7.33	7.47

Table 3A. (cont'd)

	Treatment type			
	IVF	AIH	AID	Other treatments
Support/pressure from friends and relatives	4.09	3.72	3.94	3.98
Number of consent procedures followed	6.96	2.70	6.10	2.47
Patient rating of quality of information	74.40	50.53	51.16	46.28
Patient rating of importance of information	14.71	12.46	11.67	13.22
Match of patient and clinic information priorities	8.44	3.63	3.86	4.30
Patient satisfaction	61.73	47.23	48.45	44.76
Match of patient and clinic service priorities	7.88	4.41	5.59	5.54
Rating of expectation of having a child	2.65	2.93	3.26	2.64
Rating of patient control	3.45	3.23	3.46	3.09
Rating of positive impact on patient	15.52	13.13	14.28	13.05
Rating of difficulties for patient	15.14	14.82	15.96	14.07
Rating of positive impact on spouse/partner	14.81	12.77	12.81	13.35
Rating of difficulties for spouse/partner	14.72	14.36	13.77	13.13
Patient education	13.20	13.08	13.13	13.21
Spouse/partner education	13.20	12.81	12.77	31.19
Total cost of treatments (\$)	7 221.74	3 267.65	2 586.54	2 257.51
Net cost of treatments (\$)	5 601.00	1 757.00	2 247.00	1 714.00
Months before seeking diagnosis	0.68	0.37	0.73	0.55
Months before going to clinic	2.58	1.76	1.31	1.41
Months before starting treatment	1.07	0.34	0.67	0.31
Months undergoing treatment	1.71	1.74	2.12	1.67
Total months to present (or end of treatment)	6.00	4.00	5.00	4.00

Table 3B. Fertility Problems Identified by Clinic/Doctor and Treatments Given

Diagnosis	Treatments					
	Fertility drugs	AIH	AID	IVF	Sperm wash/ IUI	Other treatment
Problem with egg production	29	19	5	15	19	7
Sperm problem(s)	27	35	72	16	37	26
Endometriosis	18	21	15	20	21	26
Problem(s) with fallopian tubes	18	15	4	53	13	21
Problem(s) with menstruation	10	12	3	4	6	8
Problem(s) with uterus	4	4	<1	3	6	2
Cervical mucus problem	6	8	4	2	11	6
Other problem	19	15	23	18	19	29
Unexplained	21	25	5	15	29	19

Table 3C. Consideration of Adoption by Current Fertility Clinic Patients* Before and During Treatment, by Treatment Type (%)

	Treatment type			
	IVF	AIH	AID	Other treatments
Applied for adoption prior to treatment	17	5	8	3
If considered adoption after starting treatments				
Completed adoption	1	0	0	0
Applied for adoption and still waiting	11	9	8	7
Applied, other (e.g., withdrew later)	4	1	9	1
Considered adoption but did not apply	28	25	26	44
Did not consider adoption or apply	39	60	49	45

* Subsample sizes: 205 (IVF); 97 (AIH); 91 (AID); 173 "other treatments".

Table 3D. Consideration of Adoption, Before and After Treatment, by Patients Whose Treatment Ended Unsuccessfully,* by Treatment Type (%)**

	Treatment type			
	IVF	AIH	AID	Other treatments
Applied for adoption prior to treatment	23	16	12	11
If considered adoption after starting treatments				
Completed adoption	0	0	0	1
Applied for adoption but not approved	0	0	1	0
Applied for adoption and still waiting	15	31	16	8
Applied, other (e.g., withdrew later)	7	2	11	12
Considered adoption but did not apply	23	22	24	32
Did not consider adoption or apply	33	29	36	36

* Subsample sizes: 190 (IVF); 98 (AIH); 35 (AID); 129 “other treatments”.

** Figures may not add to 100% due to rounding.

Table 3E. Consideration of Adoption After Treatment, by Patients Whose Treatment Ended Successfully,* by Treatment Type (%)

	Treatment type			
	IVF	AIH	AID	Other treatments
Applied for adoption prior to treatment	19	5	20	19
If considered adoption after starting treatments				
Completed adoption	1	0	1	2
Applied for adoption and still waiting	3	0	1	2
Applied, other (e.g., withdrew later)	2	0	1	1
Considered adoption but did not apply	23	31	38	18
Did not consider adoption or apply	52	64	39	58

* Subsample sizes: 138 (IVF); 33 (AIH); 57 (AID); 106 “other treatments”.

Table 3F. Approaches to Fertility that Current Fertility Clinic Patients Would Consider in Future,* by Treatment Type (%)

	Treatment type			
	IVF	AIH	AID	Other treatments
No further fertility treatments	7	4	11	11
Continue with current treatments	85	83	85	87
Fertility treatment with a private practitioner	5	7	2	2
Treatment at another clinic	20	10	11	12
Other treatment with a general practitioner	1	6	1	0
Other treatment with a specialist	6	4	3	4
Other treatment outside Canada	6	3	3	7
Pursuing adoption now	21	12	9	10
Will pursue adoption in future	24	16	14	27
Surrogacy	9	0	1	1

* Subsample sizes: 205 (IVF); 97 (AIH); 91 (AID); 173 "other treatments". Multiple responses were possible.

Table 3G. Approaches to Fertility that Patients Whose Treatment Ended Unsuccessfully* Would Consider in Future, by Treatment Type (%)

	Treatment type			
	IVF	AIH	AID	Other treatments
No further fertility treatments	43	35	39	19
Continue with current treatments	27	43	8	31
Fertility treatment with a private practitioner	3	13	11	14
Treatment at another clinic	19	21	33	22
Other treatment with a general practitioner	0	0	0	9
Other treatment with a specialist	10	18	4	12
Other treatment outside Canada	5	8	11	4
Pursuing adoption now	28	32	28	14
Will pursue adoption in future	14	21	22	18
Surrogacy	5	11	0	2

* Subsample sizes: 190 (IVF); 98 (AIH); 35 (AID); 129 "other treatments". Multiple responses were possible.

Table 3H. Approaches to Fertility that Patients Whose Treatment Ended Successfully Would Consider in Future,* by Treatment Type (%)

	Treatment type			
	IVF	AIH	AID	Other treatments
No further fertility treatments	36	35	37	47
Continue with current treatments	62	65	60	48
Fertility treatments with a private practitioner	0	0	1	11
Treatment at another clinic	5	0	1	0
Other treatment with a general practitioner	0	0	0	1
Other treatment with a specialist	1	0	0	0
Other treatment outside Canada	0	0	0	0
Pursuing adoption now	2	0	4	1
Will pursue adoption in future	4	0	1	0
Surrogacy	0	0	0	1

* Subsample sizes: 138 (IVF); 33 (AIH); 57 (AID); 106 “other treatments”. Multiple responses were possible.

Acknowledgments

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Of course, greatest thanks are extended to the over 1 400 patients of fertility clinics who shared their experiences and assessments so freely. Their participation and support in no way indicates agreement with the analysis of conclusions, which is SPR Associates' alone.

Notes

1. M.A. Belsey, "Infertility: Etiology and Natural History," in *Diagnosis and Treatment of Infertility*, ed. P.J. Rowe, and S.R. Raharinosy-Ramarozaka (Bath: Pitman Press for the World Health Organization, 1980), 12.
2. E. Muir, "Review of the Literature on the Psychosocial Implications of Infertility Treatment on Women and Men," in *Treatment of Infertility: Current Practices and Psychosocial Implications*, vol. 10 of the research studies of the Royal Commission on New Reproductive Technologies (Ottawa: Minister of Supply and Services Canada, 1993).
3. For a classic example, see J.E. Ware, Jr. and M.K. Snyder, "Dimensions of Patient Attitudes Regarding Doctors and Medical Care Services," *Medical Care* 13 (1975): 669-82. Also see J.H. Roberts and H.M. Thompson, *Satisfaction with Obstetrical Care Among Canadian Women*, report prepared for the Canadian Medical Association (Kingston: Queen's University, Department of Community Health and Epidemiology, 1987). For another view, see S. Waterworth and K.A. Luker, "Reluctant Collaborators: Do Patients Want to Be Involved in Decisions Concerning Care?" *Journal of Advanced Nursing* 15 (1990): 971-76.
4. Only one study provides any national perspective, and it focusses more on clinical aspects of treatment and results. See J. Collins, E. Burrows, and A. Willan, "Infertile Couples and Their Treatment in Canadian Academic Infertility Clinics," in *Treatment of Infertility: Current Practices and Psychosocial Implications*, vol. 10 of the research studies of the Royal Commission on New Reproductive Technologies (Ottawa: Minister of Supply and Services Canada, 1993).
5. See Muir, "Review of the Literature"; and J. Wright et al., "Psychosocial Distress and Infertility: A Review of Controlled Research," *International Journal of Fertility* 34 (1989): 126-42.
6. See J. Wright, "The Psychosocial Impact of New Reproductive Technology," in *Treatment of Infertility: Current Practices and Psychosocial Implications*, vol. 10 of the research studies of the Royal Commission on New Reproductive Technologies (Ottawa: Minister of Supply and Services Canada, 1993). Portions of this and related work by Wright are also reported in a variety of journal publications.

7. See, for example, L.S. Williams, "Wanting Children Badly: An Exploratory Study of the Parenthood Motivation of Couples Seeking In Vitro Fertilization," Ph.D. dissertation, University of Toronto, 1988.
8. See Decima Research, "Social Values and Attitudes of Canadians Toward New Reproductive Technologies," in *Social Values and Attitudes Surrounding New Reproductive Technologies*, vol. 2 of the research studies of the Royal Commission on New Reproductive Technologies (Ottawa: Minister of Supply and Services Canada, 1993).
9. Attempting to capture this complexity in an 11-page questionnaire was most challenging and created a variety of data recording difficulties, many of which had to be solved using coding procedures. (Some of these complexities are detailed in Appendix 2.)
10. See T. Stephens and J. McLean, "Survey of Canadian Fertility Programs," in *Treatment of Infertility: Current Practices and Psychosocial Implications*, vol. 10 of the research studies of the Royal Commission on New Reproductive Technologies (Ottawa: Minister of Supply and Services Canada, 1993).
11. Taken in part from A. Rochon Ford, "A Socio-Historical Examination of the Development of In Vitro Fertilization and Related Assisted Reproductive Techniques," in *Treatment of Infertility: Assisted Reproductive Technologies*, vol. 9 of the research studies of the Royal Commission on New Reproductive Technologies (Ottawa: Minister of Supply and Services Canada, 1993).
12. Taken in part from Stephens and McLean, "Survey of Canadian Fertility Programs".
13. "Private" refers to a clinic operating independently of a publicly funded hospital.
14. These numbers do not include solo practitioners in Canada who offer fertility treatments, (e.g., fertility drugs or AI) outside fertility clinics.
15. See, for example, S.M. Webb, "Survey of Women on Issues Surrounding Their In Vitro Fertilization Treatment," Occasional paper 35 (Perth: Health Department of Western Australia, 1989); Wright et al: "Psychosocial Distress and Infertility"; Collins et al., "Infertile Couples and Their Treatment."
16. Alpha, or Cronbach's Alpha, is an estimate of reliability based on the internal consistency of the responses given to a multi-item indicator. It is based on the assumption that if a number of questions or items measure the same thing, this will be reflected in high inter-item correlations and that reliability will be higher if more items are used in a scale. Alpha is an estimate of item scale correlations based on correlation of all possible subsets (split halves) of items. Generally, an Alpha in excess of 0.7 is regarded as indicating good reliability. For an explanation of factor analysis, see note 30.
17. See Stephens and McLean, "Survey of Canadian Fertility Programs."
18. Document quality and readability analyses were provided by Stephens and McLean for English language materials only.
19. The main treatment groups used in this analysis actually include some who received a variety of treatments. For example, the IVF group included a large portion of patients who had previously received AIH or AID.

20. M.B. Hirsch and W.D. Mosher, "Characteristics of Infertile Women in the United States and Their Use of Infertility Services," *Fertility and Sterility* 47 (1987): 618-25; and S.L. Laurent et al., "An Epidemiologic Study of Smoking and Primary Infertility in Women," *Fertility and Sterility* 57 (1992): 565-72.
21. P. Manga, R.W. Broyles, and D.E. Angus, "The Determinants of Hospital Utilization Under a Universal Public Insurance Program in Canada," *Medical Care* 25 (1987): 658-70; R.F. Badgley, "Social and Economic Disparities Under Canadian Health Care," *International Journal of Health Services* 21 (1991): 659-71.
22. Statistics Canada reports a quite different national distribution of income for families (which would include both "younger" and "older" females). Among all families in 1990, about 35% had incomes under \$30 000, and only about 25% had incomes over \$50,000, suggesting substantially higher incomes than average among those obtaining fertility treatments (see Canada, Statistics Canada, *Income Distribution by Size in Canada, 1990*, Cat. No. 13-207 (Ottawa: Minister of Industry, Science and Technology, 1991).
23. See L.S. Williams, "Adoption Actions and Attitudes of Couples Seeking In Vitro Fertilization," *Journal of Family Issues* 13 (1992): 99-113.
24. Technically, only physicians can refer patients. "Referral" is used here in both the non-technical and the technical senses.
25. See Wright, "The Psychosocial Impact of New Reproductive Technology."
26. See Muir, "Review of the Literature"; and Wright, "The Psychosocial Impact of New Reproductive Technology."
27. It should be remembered that patients attending specialized infertility clinics are not necessarily typical of infertile couples in general, rather they are the infertile couples whose initial treatments have generally been unsuccessful.
28. It is not possible, with the specific survey information collected, to calculate one part of this sequence — the length of time elapsed between seeking a diagnosis and obtaining a diagnosis.
29. The percentages of patients who rated each type of information as "having been provided" and "good to excellent" were computed. "Good to excellent" was defined as points four and five on the five-step scale, three was "adequate," and five was "excellent." The remainder of these percentages included patients reporting "no information provided" for each topic, and patients reporting that information was provided for each topic but it was "poor" to "adequate."
30. Factor analysis is a statistical technique designed to identify basic indicators that describe a number of variables. It describes the minimum number of dimensions or factors required to describe a field of data as summarized by the correlations among the variables and their variance/co-variance. Our factor analysis describes a number of key factors; overall clinic performance is the one that accounted for the most variance for most variables. It comprises such indicators as total amount of information given, amount of time the patient was given to think over decisions, amount of counselling/support the patient was given, number of formal consent procedures, satisfaction with quality of information, and satisfaction with services provided. (Other factors identified include the match of clinic information and services to patient priorities; the extent of treatments/consultations before attending the present clinic; the positive effects on

patient and spouse/partner; the difficulties experienced by patient and spouse/partner in treatment; and the length of time seeking and receiving fertility treatments.)

31. The multivariate analysis (discriminant analysis) provides a simultaneous view of many variables, in a statistical model somewhat similar to multiple regression but more appropriate for qualitative data. It examines a number of control variables and simultaneous assessments of their impact (e.g., IVF treatment versus other treatments) to control for the differences in treatments such as length of time undergoing treatment, and classifies patients according to their level of satisfaction.

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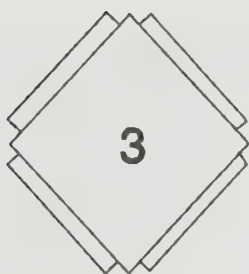
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Infertile Couples and Their Treatment in Canadian Academic Infertility Clinics

John Collins, Elizabeth Burrows, and Andrew Willan



Executive Summary

The three reports that make up this study provide data gathered through the Canadian Infertility Therapy Evaluation Study (CITES). The study collected data on the personal characteristics (age, income, occupation, etc.) of some 2 200 infertile couples who registered at infertility clinics associated with medical schools in 11 Canadian cities, as well as the diagnoses and treatments they received and the outcome for the couples by the end of the study period.

CITES began as a randomized trial, but it became evident that the couples and their doctors were not ready to accept such an approach to evaluating infertility treatment. Therefore, the study continued as *in situ* research. After registering at an infertility clinic, couples received diagnosis and treatment and their progress was followed for up to four years after registration.

The period covered by the initial study was 1 April 1984 to 31 March 1987. Data for five of the clinics (these clinics accounted for about 70% of the couples studied) were updated to September 1991 and incorporated in the study results.

Report 1 describes the demographic characteristics of the couples studied, any reason or reasons identified for their infertility, the nature

of the treatment they received, and the outcome — whether a pregnancy occurred; whether a live birth resulted; whether the couple chose another alternative, such as adoption; or whether the couple continued to be under observation or treatment. The report also considers the effects of such factors as how long the couple had been trying to conceive before seeking treatment, and the length of time between diagnosis and treatment.

Report 2 presents the results of an evaluation of the effects of several types of infertility treatment in couples with different diagnoses and personal characteristics. This report also examines how particular diagnoses or personal characteristics influence decisions about whether and how to treat infertility.

Report 3 contains updated data for couples whose progress was followed after the end of the initial study period. The results presented in the first two reports take these updated data into account.

Report 1: Clinical and Demographic Characteristics of the Infertile Couples

Background

Beginning in 1981, a group of investigators supported by feasibility funding from the National Health Research and Development Program began to consider issues in the design and methodology of a trial of infertility therapy in Canada. Methodology experts from the University of Calgary, the University of Western Ontario, McMaster University, the University of Waterloo, and Dalhousie University contributed to the final design by which couples meeting the eligibility criteria would be randomized to receive indicated treatment either immediately or after a six-month delay.

The possibility that such a design might not be acceptable was discussed, and it was decided that the trial would be run in conjunction with a follow-up study of couples in the individual clinics. The follow-up study would fulfil the need to examine whether couples accepting randomization were reasonably typical, and following up on couples who did or did not receive treatment, even if their allocation was not random, would provide information that was not as yet available.

The historical context at that time was that there were virtually no randomized clinical trials of infertility therapy available, and the understanding of treatment-independent pregnancy was limited to a few small publications.

After the funding period began, only 12 couples were successfully randomized during the first year, and it became evident that infertile couples and their doctors were not yet ready to accept such studies to evaluate infertility treatment. The Canadian Infertility Therapy Evaluation Study (CITES), therefore, continued as a form of *in situ* research, in which

couples received diagnosis and treatment within a broadly defined clinical protocol and were followed during the course of one to four years following registration at an academic infertility clinic in Canada.

A cohort study such as this one provides much weaker evidence in establishing cause-and-effect connections between treatment and pregnancy. The main source of potential bias derives from the decision to treat (or request for treatment), which is not determined by random allocation. As a result, couples in the treated and untreated groups may not be comparable. Thus, some caution must be used when evaluating the effectiveness of the infertility treatments experienced by couples in this study. Since a cohort study is viewed as sub-experimental, it can only establish an association between treatment and pregnancy.

Methods

Design and Setting

The study was a prospective observational study of infertile couples attending infertility clinics associated with medical schools in 11 Canadian cities: Centre hospitalier universitaire de Sherbrooke, University of Sherbrooke; Hôpital St-François d'Assise, Laval University; Royal Victoria Hospital Infertility Centre, McGill University; St. Paul's Hospital, University of British Columbia; University Hospital, University of Western Ontario; Royal University Hospital, University of Saskatoon; Foothills Hospital, University of Calgary; Grace Maternity Hospital, Dalhousie University; Kingston General Hospital, Queen's University; McMaster University Medical Centre; and Ottawa Civic Hospital, University of Ottawa. Enrolment took place from 1 April 1984 through 31 March 1987, and follow-up for the first draft of this report was completed on 31 March 1988. Using the data summarized in Report 3, the follow-up has been updated to 30 September 1991 for five centres: Foothills Hospital, University of Calgary; Grace Maternity Hospital, Dalhousie University; Kingston General Hospital, Queen's University; the McMaster University Medical Centre; and the Ottawa Civic Hospital, University of Ottawa, which enrolled 1 567 of the original 2 198 couples.

Patients

The patients were couples registering for the first time with a complaint of infertility of more than one year's duration. Excluded were couples with a history of sterilization in either partner or recurrent spontaneous pregnancy loss. The proportion of new couples at each clinic who were registered in the study varied from clinic to clinic as a result of local referral patterns and co-existing clinical studies.

Clinical Procedures

The diagnostic protocol included repeated semen analysis, luteal-phase progesterone estimation or endometrial biopsy, prolactin estimation, hysterosalpingogram, and laparoscopy. Laparoscopy was performed as the

initial assessment under the following circumstances: a history of pelvic pain or infection, abnormal findings on pelvic examination or abnormal hysterosalpingogram, or infertility of more than 36 months' duration. Otherwise, laparoscopy was performed if conception did not occur within one year of registration.

After completion of the diagnostic protocol, couples were given treatment according to the clinical indications and were kept under observation. Pregnancy, study termination, loss to follow-up, adoption, and discontinued interest were the study outcome events. For the purpose of these analyses, pregnancy is the event of interest; other outcomes were not analyzed.

Clinical Definitions

The *age of female and male partners* was their age at the time of registration, not at the time conception attempts were started. Pregnancy history was defined as follows: *primary infertility* implies no history of pregnancy in the partnership (when there was a prior pregnancy for the female partner in a previous partnership, that was also classified as primary infertility); *secondary infertility* (PREGHIST) implies any previous pregnancy in the partnership, regardless of the pregnancy outcome. *Duration of infertility* was the interval (in months) from discontinuation of contraceptive use until registration in the participating clinic. *Ovulation disorder* includes amenorrhoea, oligomenorrhoea, and irregular cycles with intervals greater than 42 days. *Seminal defect* was defined as one or more of the following: sperm density less than 20 million per millilitre, less than 40 percent of sperm with progressive motility, or less than 40 percent morphologically normal sperm. *Endometriosis* was defined according to the 1979 American Fertility Society criteria in use at the beginning of the study. *Tubal disease* was defined after laparoscopy as adhesions, or partial or complete obstruction. In some of the analyses presented here, endometriosis and tubal disease were classified together as *adnexal disease*.

Occupational Definitions

Male and female occupations were recorded at the time of the initial interview. Occupations were classified using three indigenous coding systems:

1. The Blishen scale

Our initial approach was based on the occupational classification published by Blishen and McRoberts (1976). The Blishen scale ranks occupations in Canada based on employment income and education level attained. The coded data consist of 360 individual categories for male and female occupations. The occupations were grouped according to the higher of the two partners' occupation levels into quartiles to make up a "social level" variable: upper, upper middle, lower middle, and lower. Although somewhat dated, the scale is still useful for comparing adjacent and nearby rankings (Olshan et al. 1990).

2. Population and Dwelling Characteristics: Occupation (Canada, Statistics Canada 1989a)

Based on a 20 percent sub-census in 1986, this publication reports on the employed Canadian population by age, sex, and other selected dwelling and regional characteristics according to 514 individual occupations. For our analysis, the data for each sex in the Canadian population were adjusted for the age distribution of the infertile partners. The classification structure is hierarchical so that comparisons could be made between our data and the Canadian population by sex at three levels of aggregation:

- (a) 514 detailed categories;
- (b) 20 groups, with an additional group to include those who were unemployed, students, or housewives; and
- (c) three major occupational categories for each sex — professional, sales and services, and industrial and resources.

In the infertile group, a fourth category was added for the unemployed (including students and housewives).

This approach yielded a set of variables for male occupations and a second set for female occupations.

3. Income levels

- (a) *Population and Dwelling Characteristics: Employment Income by Occupation* (Canada, Statistics Canada 1989b): This publication reports on average income in 1985 by sex, work activity, detailed occupation, and age group. These data were also adjusted within each sex for the age distribution of the infertile partners. We used this information to estimate male and female incomes, and family income was computed as the total of the male and female incomes.

- (b) *Demographic and Income Statistics for Postal Areas: Ontario 1988* (Canada, Statistics Canada 1990): This publication reports demographic and income statistics for postal areas, also based on the 20 percent sub-census in 1986. For several years during the study, it was the policy of one Ontario clinic in our study not to ask couples for information about their occupations. Most of our missing data on occupation arise from that clinic. Median employment income by postal code and by sex but not by age (since that information is not available) was used to estimate the income for those couples with missing occupational information. Male and female incomes were then age-adjusted using the average employment income for each age group. For this purpose we used the following average incomes for all Canadian occupations by sex and age group, 1986 sub-census:

Age group	Males (\$)	Females (\$)
15-24	17 000	14 000
25-44	30 700	21 100
45-64	33 800	20 500

Statistical Analysis

The influence of clinical and demographic variables, including occupation, on pregnancy was evaluated first in univariate analyses. The following is a list of the variables that were evaluated.

A. Status or outcome

1. pregnant — yes or no
2. treated — yes or no
3. outcome of the pregnancy (PRGOUTCM) — live birth, spontaneous abortion, ectopic, or still pregnant at last follow-up
4. status — pregnant, not pregnant (continuing under observation or treatment), not pregnant (discontinued interest in treatment during follow-up), adopted, or lost to follow-up (discontinued follow-up without notice).

B. Clinical and demographic characteristics

1. duration of infertility (DURATION) — the number of months that the couple had been attempting pregnancy at the time of registration
2. age of male (MALEAGE) and female (FEMAGE) partners — the number of years at the time of registration
3. pregnancy history (PREGHIST) — whether the couple has had a previous pregnancy in the partnership or not
4. history of contraceptive use — yes or no; history of intrauterine device use — yes or no; history of oral contraceptive use — yes or no
5. history of infertility treatment in either partner prior to registration (MPREVTMT, FPREVTMT) — yes or no
6. coital frequency (COITFREQ) — less than once a week, once a week, two to six times a week, or more often. This variable was then re-coded into the categories (less than twice per week and all others) and the new variable was labelled LT2PERWK.
7. menstrual cycle frequency (CYCLES) — under 25 days, 25-35 days, over 35 days, irregular

8. laparoscopy done (LAP) — yes or no
9. centre where couple was registered (CENTRE) — the 11 infertility clinics

C. *Clinical diagnosis*

1. diagnoses for any of the following disorders:
 - (a) ovulatory deficiency (OVDEF) — oligo-ovulation, amenorrhoea;
 - (b) hyperprolactinemia (HYPRLECTN);
 - (c) tubal deficiency (TUBDEF) — adhesions, partial obstruction, bilateral obstruction;
 - (d) seminal deficiency (SEMDEF) — oligospermia, azoospermia;
 - (e) endometriosis (ENDOSIS) — mild, moderate, or severe endometriosis;
 - (f) luteal-phase defect (LUTDEF) — documented in one or more than one cycle; and
 - (g) other (OTHER) — uterine or cervical defect.
2. primary clinical diagnosis (PCD) — one of the preceding diagnoses or unexplained infertility (UNEXPLND) if none of the above diagnoses was made; for couples with more than one infertility diagnosis, the more severe disorder as indicated by the clinic physician was the primary clinical diagnosis

D. *Socioeconomic status*

Occupations:

1. occupations of the male and female partners using Statistics Canada occupation codes grouped into 20 areas of employment (listed in Table 1.7); the codes are the basis for grouping males and females into professionals (MPRFESNL, FPRFESNL), services (MSERVICE, FSERVICE), industrial workers (MNDUSTRL, FNDUSTRL), or unemployed (MUNMPLYD, FUNMPLYD)
2. occupations of the male and female partners using the Blishen method of ranking socioeconomic index with scores from 1 to 500; quartiles of the Blishen scale were obtained by grouping couples

Income:

3. incomes of the male and female partners based on Statistics Canada estimates of income using occupation codes adjusted by age and sex

4. couples with missing occupational information — income was estimated using Statistics Canada estimates of income by postal area and by sex (these data were not available based on age)
5. two binary variables for income were computed as follows: individual CITES male income was compared with the average income of Canadian males of the same age group to determine if it was higher or lower. This was repeated for CITES female income. The process was repeated substituting estimates of income derived from postal code incomes for cases with missing data. These age-adjusted income variables were used only in preliminary analyses; other income variables were more informative
6. family income (INCOME) — measured by adding the male and female partners' incomes
7. family income levels (INCOMGRP) — obtained by dividing family income into quartiles

E. Time variables

1. time under observation (TIMEOBSN) — the number of months the infertile couple was followed from the date of registration to conception, last visit/contact, loss to follow-up, discontinued interest (resolved), or adoption
2. time to laparoscopy (TIMETOLAP) — the number of months from registration to the date of the laparoscopy procedure (for laparoscopies done prior to registration, the time is negative). When used as a time dependent variable, time to laparoscopy was labelled XTIMLAP

F. Treatment variables

The summary treatment variables are described in this report because treatment was included in the prognosis analyses as a single time-dependent variable. A more complete description of the treatments is found in Report 2.

1. any type of recognized infertility treatment, including clomiphene, surgery, artificial insemination, *in vitro* fertilization (IVF), Danazol[®], Pergonal[®], etc.
2. time to treatment (TIMTORX) — the number of months from the time of registration to the date that the first treatment (clomiphene, surgery, IVF, etc.) was started. There are also time variables to measure the time from registration to the starting date of a second, third, etc. treatment. When used as a time dependent variable, time to treatment was labelled XTIMERX

- 3. time on treatment — the number of months (or cycles) from the time a treatment was started to the time the treatment was stopped

Proportional Hazards Analysis

The strategy for selecting variables to include in the proportional hazards analysis was based on both univariate analysis and multiple step-wise regression. In the latter, all variables were introduced into each model to predict pregnancy, treatment, or laparoscopy, and the important ($p < 0.10$) baseline patient characteristics were identified. In the proportional hazards analyses, pregnancy, treatment, and laparoscopy status were entered as time-dependent variables.

The analyses were stratified by study centre. Use of dummy codes for clinics, rather than stratification, assumes proportional hazards between clinics. Since we are interested only in controlling for differences in clinics, rather than in testing for the effect of the clinics, stratification, with its less stringent assumptions, is all that is required. (Confounding by centre with respect to family income and patient characteristics is tested in a later section.) To obtain a relative risk, variables were dichotomized on the median in some analyses. Some categorical variables were recoded to two categories. The dichotomized variables are:

- 1. pregnancy history as a binary variable: couple had a previous pregnancy (= 1) versus no previous pregnancy in this partnership (= 0);
- 2. sexual activity as a binary variable: inadequate — less than twice weekly (= 1) versus adequate (= 0);
- 3. presence of tubal disease, endometriosis, ovulation deficiency, seminal deficiency as binary variables (yes (= 1) versus no (= 0));
- 4. duration of infertility as a binary variable (less than 36 months (= 1) versus equal to or greater than 36 months (= 0));
- 5. age groups for male and female partners as binary variables (less than 30 years (= 1) versus equal to or greater than 30 years (= 0));
- 6. the total number of motile sperm in the ejaculate as a binary variable (total motile count less than 20 million (= 1) versus equal to or greater than 20 million (= 0)); and
- 7. previous infertility treatment prior to registration for either male or female partner as a binary variable (yes (= 1) versus no (= 0)).

The association between socioeconomic status and pregnancy was evaluated using the proportional hazards model in the following ways:

- 1. three dummy variables (0 = not present, 1 = present) are used to represent a four-level discrete variable based on male occupation:

professional occupations	(MPRFESNL)	1	0	0
services occupations	(MSERVICE)	0	1	0

industrial occupations	(MNDUSTRL)	0	0	1
unemployed	(MUNMPLYD)	0	0	0

The preceding was repeated in the same way for female occupations: FPRFESNL, FSERVICE, FNDUSTRL, FUNMPLYD;

- 2. three dummy variables were used to represent the socioeconomic ranking of the higher-ranking partner using the quartiles of the Blishen scale. Then one binary variable, obtained from dichotomizing the four levels into two — high (= 1) and low (= 0) — was introduced into the analysis. (These variables contributed little to the model, and the results with respect to outcome are not tabulated here);
- 3. two binary variables (MALEAVG, FEMALEAVG) were used to represent age-adjusted income for males and for females. Each was computed by classifying income as above, equal to, or below the income average by comparing estimated income with the average Canadian income by sex and age group. The analysis was repeated, substituting missing incomes with postal code incomes. Neither of these variables contributed significantly to the model, and these were dropped from further analysis; and
- 4. total family income (INCOME) was evaluated by entering this continuous variable in tens of thousands of dollars (e.g., if a family had a total income of \$68 500, then the value entered for that family was 6.85). If we were to estimate missing family income using the incomes based on postal codes, the computed income would be overstated because the postal code data assume both partners to be earning income. We conducted a proportional hazards analysis (not presented) in which family income for couples with missing occupational information was based on the sum of male postal code income and 0.5 times the female postal code income. In this analysis, the contribution of income, adjusted for the effect of other variables, was not materially changed from the estimates based on available data.

Section 1: Clinical Description by Centre (Tables 1.1-1.6)

Clinical Characteristics of 2 198 Couples Attending 11 Canadian Academic Infertility Clinics

During this study, couples attending infertility clinics in health sciences centres in Canada had an average duration of infertility of 42 months (Table 1.1). The mean age of female partners was 29.5 years, and that of male partners was 31.9 years. Couples remained under observation, after updating, for a mean of 26 months. For couples who had treatment, the average time to treatment was 7.4 months.

Table 1.1 Clinical Description of 2 198 Couples Attending 11 Canadian Academic Infertility Clinics

Clinical variable	Mean	S.D.	Range among 11 clinics
Duration of infertility (months)	41.9	27.2	30.3-49.1
Female partner's age (years)	29.5	4.2	27.6-31.3
Male partner's age (years)	31.9	4.8	29.8-33.3
Observed time (months)	26.0	22.9	13.0-39.1
Time to treatment (months)	7.4	8.6	3.5-11.5
	Number	%	Range among 11 clinics (%)
Secondary infertility	493	22.4	16-32
Coital frequency less than twice per week	362	16.4	9-23
Primary clinical diagnosis			
Ovulation defect	424	19.3	9-36
Seminal defect	525	23.9	14-43
Tubal defect	509	23.2	16-28
Endometriosis	146	6.6	2-25
Other	32	1.5	0-5
No abnormality detected (unexplained infertility)	562	25.6	8-37
Had laparoscopy	1 380	62.8	40-93
Received treatment	1 325	60.3	44-81
Lost to follow-up	291	13.2	3-32
Became pregnant	866	39.4	25-48

S.D. — standard deviation

The range of means for the above-noted variables among the 11 clinics suggests that there are important differences in the clinical features of the patients referred to these clinics. Such differences may also be expected to affect pregnancy rates, because factors such as duration of infertility are known to have a bearing on the expectation of pregnancy.

Secondary infertility is defined as failure to conceive during one year without the use of contraception, when there has been a history of a pregnancy with or without successful delivery in that partnership in the past. Twenty-two percent of the couples had secondary infertility, and a further 10 percent gave a history of pregnancy in another partnership.

Sixteen percent of the couples gave a history of coital frequency less than twice per week before registration. Further information on the frequency of intercourse was not obtained during follow-up.

Clinicians were asked to identify the most important diagnosis in each case, which is labelled the primary clinical diagnosis (PCD). The distribution of primary clinical diagnoses, as shown in Table 1.1, is within the range expected from published reports during the last decade.

The performance of laparoscopy is dictated by clinical conditions and patients' wishes. Some couples conceived before a laparoscopy could be completed; thus, although laparoscopy is considered the benchmark of a complete investigation of infertility, it was not performed in all couples attending the infertility clinics. The frequency of laparoscopy performance ranged from 40 percent to 93 percent in the 11 Canadian centres.

Similarly, treatment depends on the clinical indications and patients' wishes. The treatment rates ranged from 44 percent to 81 percent; overall, 1 325 couples (60%) received treatment. Further details on treatment are the subject of Report 2.

Loss to follow-up is relatively common in studies of infertility. First, interurban mobility is relatively common in this age range. Second, infertility treatment is influenced by personal feelings, and some couples may decide informally to discontinue clinical management. During the update of infertile couples at the five participating centres, we were able to contact some patients who had previously been considered lost to follow-up. The overall average rate dropped by seven percentage points to 13 percent (291 couples), and the percentage of couples who discontinued their follow-up without notice ranged from 3 percent to 32 percent in the 11 clinics.

The number of pregnancies among the 2 198 couples was 866 (39%). There were 340 pregnancies among the 873 couples who did not receive treatment and 526 pregnancies among the 1 325 couples who did receive treatment.

All Clinical Diagnoses

During the course of the investigation of infertility, one or more defects in ovulation, seminal production, tubal function, or endometriosis may be described. As more than one diagnosis may be found in an individual couple, it is also important to categorize all diagnoses found. In Table 1.2, ovulation, seminal, and other defects are arranged according to severity, and the number and percentage of couples in each category are given. Although 562 couples (25.6%) received no explanation for their infertility after a conventional diagnostic assessment, there were, on average, 1.4 diagnoses per couple, or 1.7 per couple for those where some cause for infertility was found.

Table 1.2 All Clinical Diagnoses Among 2 198 Couples Attending 11 Canadian Academic Infertility Clinics

Clinical diagnosis	Number	%
Ovulation defects		
oligo-ovulation	470	20.9
amenorrhoea over six months	42	1.9
hyperprolactinemia	58	2.6
luteal-phase defect	26	1.2
Subtotal	596	26.5
Seminal defect		
oligospermia	448	19.9
azoospermia	156	6.9
Subtotal	604	26.9
Tubal defect		
adhesions only, no obstruction	114	5.1
unilateral or partial obstruction	250	11.1
bilateral tubal obstruction	214	9.5
Subtotal	578	25.7
Endometriosis		
Stages I & II (minimal, mild)	224	10.0
Stage III (moderate)	55	2.4
Stage IV (severe)	33	1.5
Subtotal	312	13.9
Other possible defects		
cervical	89	4.0
uterine	68	3.0
Subtotal	157	7.0
Total defects	2 247 ¹	100.0
Unexplained infertility	562	
All diagnoses	2 809	

¹ A couple could have one or more defects but only one primary clinical diagnosis. Defects per couple: $2\,809 \div 2\,198 = 1.3$.

Detailed Clinical Information by Infertility Clinic

Tables 1.3-1.6 provide the number of patients in each clinic and their clinical characteristics (Tables 1.3(a) and 1.3(b)); the distribution of primary clinical diagnoses, including unexplained infertility (Table 1.4); the number of months under observation, number of months to start of treatment, and proportion lost to follow-up (Table 1.5); and details of procedures and outcomes, including frequency of treatment, overall pregnancy rates, and pregnancy rates for those treated and not treated (Table 1.6). The treated rate includes all pregnancies that occurred in the treatment group, even though in some cases conception may have occurred after treatment stopped. Significant variability was observed between the clinics with respect to virtually all clinical characteristics, observations made, and outcomes.

Table 1.3(a) Clinical Characteristics of 2 198 Infertile Couples, Arranged by Infertility Clinic: Duration of Infertility and Age of Female and Male Partners

Infertility clinic	Valid number	Duration of infertility (months)		Female partner's age (years)		Male partner's age (years)	
		Mean	S.D.	Mean	S.D.	Mean	S.D.
Sherbrooke	133	30.8	16.9	27.6	3.6	29.8	4.2
Calgary	92	32.6	20.0	29.1	3.8	30.6	4.3
Dalhousie	473	41.0	25.7	28.8	3.9	31.3	5.0
Laval	114	39.9	26.7	29.3	4.2	30.9	4.1
Queen's	88	40.4	26.5	30.1	4.1	32.4	4.8
McMaster	729	49.1	30.4	30.3	4.1	32.7	4.8
Ottawa	185	30.3	19.6	29.9	3.9	32.3	5.0
McGill	92	38.7	30.7	30.5	5.0	33.3	5.8
UBC	89	38.5	26.8	31.3	4.1	32.9	4.4
UWO	116	45.3	25.7	28.4	3.9	30.9	3.7
Saskatoon	87	41.9	22.2	28.6	4.7	31.3	5.4
Total	2 198						
Overall mean, S.D.		41.9	27.2	29.5	4.2	31.9	4.8
F		13.1		11.3		8.5	
p*		< 0.0005		< 0.0005		< 0.0005	

* In this and subsequent tables, the p value associated with the variance ratio (F) represents the significance level for testing equality of means between clinics (i.e., the probability of observing means as different from these if patients had been randomly assigned to clinics).

Table 1.3(b) Clinical Characteristics of 2 198 Infertile Couples, Arranged by Infertility Clinic: Secondary Infertility, Contraceptive Use, Coital Frequency, and Previous Treatment

Infertility clinic	Valid number	Secondary infertility (%)	Previous oral contraceptive use (%)	Previous intrauterine device use (%)	Coitus less than twice per week (%)	Previous treatment of either partner (%)
Sherbrooke	133	21.8	82.7	20.3	23.3	18.8
Calgary	92	16.3	90.2	25.0	19.6	13.0
Dalhousie	473	17.8	84.4	16.7	12.3	25.6
Laval	114	31.6	82.5	22.8	8.8	28.9
Queen's	88	28.4	84.1	17.0	10.2	22.7
McMaster	729	25.5	73.5	17.5	17.3	58.8
Ottawa	185	19.5	87.6	24.3	27.0	24.3
McGill	92	27.2	62.0	13.0	18.5	27.2
UBC	89	23.6	86.5	32.6	16.9	33.7
UWO	116	19.0	86.2	17.2	12.1	56.9
Saskatoon	87	16.1	77.0	14.9	16.1	46.0
Total	2 198					
Overall percentage		22.4	80.1	19.0	16.5	38.5
χ^2 (10 df)		24.2	63.2	23.6	35.9	269.8
p*		0.0070	< 0.00005	0.0089	0.0001	< 0.00005

* In this and subsequent tables, the p value associated with χ^2 represents the significance level for testing the equality of distributions between clinics (i.e., the probability of observing frequency distributions as different from these if patients had been randomly assigned to clinics).

Table 1.4 Primary Clinical Diagnosis (PCD) Arranged by Infertility Clinic

Infertility clinic	Valid number	PCD (%)				
		Ovulation	Seminal	Tubal	Endometriosis	Other ¹
Sherbrooke	133	23.3	42.9	15.8	4.5	3.0
Calgary	92	13.0	18.5	20.7	12.0	4.3
Dalhousie	473	22.2	18.0	20.7	4.7	1.1
Laval	114	20.2	14.0	24.6	25.4	3.5
Queen's	88	13.6	35.2	20.5	9.1	0.0
McMaster	729	15.2	18.8	28.3	5.3	0.5
Ottawa	185	35.7	29.7	21.6	4.9	0.0
McGill	92	25.0	23.9	23.9	2.2	4.3
UBC	89	9.0	37.1	15.7	0.0	1.1
UWO	116	15.5	29.3	23.3	11.2	1.7
Saskatoon	87	17.2	43.7	18.4	8.0	4.6
Total	2 198					
Overall percentage		19.3	23.9	23.2	6.6	1.5
$\chi^2 = 331.6, 50 \text{ df}, p < 0.0005$						
Unexplained						
						10.5
						31.5
						33.4
						12.3
						21.6
						31.8
						8.1
						20.7
						37.1
						19.0
						8.0

¹ A breakdown of this category is presented in Table 2.2.

Table 1.5 Time Under Observation in Clinic, Time from Registration to Start of Treatment, and Percentage of Couples Lost to Follow-up, Arranged by Infertility Clinic

Infertility clinic	Valid number	Observed time (months)		Time to treatment (months)		Lost to follow-up (%)
		Mean	S.D.	Mean	S.D.	
Sherbrooke	133	14.7	8.7	5.7	4.4	23.3
Calgary	92	19.6	11.7	10.7	5.4	16.3
Dalhousie	473	15.9	11.3	6.6	6.1	7.0
Laval	114	20.6	12.7	3.5	3.8	20.2
Queen's	88	21.6	11.5	9.6	7.7	8.0
McMaster	729	13.1	9.6	5.8	6.2	12.1
Ottawa	185	16.5	11.1	7.4	5.6	8.1
McGill	92	13.0	9.4	7.4	4.6	29.3
UBC	89	16.7	10.1	5.8	4.7	31.5
UWO	116	14.0	9.8	4.0	2.8	18.1
Saskatoon	87	17.2	12.9	5.4	5.1	3.4
Total	2 198					
Overall mean, S.D.		15.4	10.8	6.1	5.8	13.2
F		12.1		8.3		
χ^2 (10 df)						96.8
p			< 0.00005		< 0.0005	< 0.00005

Table 1.6 Procedures and Outcomes, Arranged by Infertility Clinic

Infertility clinic	Laparoscopy completed					
	Valid number	Laparoscopy completed (%)	after registration (%)	Treatment received (%)	Number pregnant	Total pregnancy rate (%)
Sherbrooke	133	28.6	21.8	55.6	44	33.1
Calgary	92	69.6	65.2	43.5	39	42.4
Dalhousie	473	56.7	35.5	51.0	201	42.5
Laval	114	82.5	60.5	80.7	47	41.2
Queen's	88	93.5	65.9	45.5	38	43.2
McMaster	729	71.5	22.4	68.3	285	39.1
Ottawa	185	59.5	43.2	57.8	82	44.3
McGill	92	40.2	32.6	47.8	36	39.1
UBC	89	43.8	14.6	57.3	22	24.7
UWO	116	69.8	38.8	63.8	30	25.9
Saskatoon	87	56.3	36.8	73.6	42	48.3
Total	2 198					
Overall percentage		62.9	34.0	60.3	866	39.4
χ^2 (10 df)		191.8	192.5	90.6		26.9
p		< 0.00005	< 0.00005	< 0.00005		0.0027
						0.12
						0.0002
						38.9
						34.5
						26.1
						16.7
						21.1
						43.8
						55.1
						33.8
						43.8
						36.4
						41.6
						42.5
						40.9
						41.3
						39.4
						45.7
						44.2
						30.5

Section 2: Socioeconomic Status: Comparison with Employed Canadians and Relationship with Clinical Characteristics (Tables 1.7-1.19)

This section uses information provided by each clinic on the occupations of the male and female partners of the infertile couples. At the beginning of the study, in 1984, the only reference comparison for the Canadian population was the Blishen scale (Blishen 1968; Blishen and McRoberts 1976). More recently, information on occupations in Canada has become available, based on a 1986 sub-census. Because the information was compiled near the midpoint of enrolment for this study, it is particularly relevant to this group of infertile couples.

Tables 1.7-1.12 include comparison data, arranged by occupation, income, and quartiles of the Blishen scale, as well as various expressions of income. The four sub-tables grouped under Table 1.13 give details of the percent distribution of male occupation, female occupation, Blishen-scale quartiles, and family income quartiles by infertility clinic.

The key tables in this section are Tables 1.14-1.18, which replicate Tables 1.3-1.6, describing the clinical characteristics, management, observations, and outcomes of the infertile couples, in this case with respect to quartiles of family income.

Comparison of Occupations Between Infertile Couples and Employed Individuals in Canada

Tables 1.7 and 1.8 compare the distribution of occupations of the couples in the infertility clinics with data for Canada as a whole in 1985. We have also attempted to compare occupations in one clinic with occupations in the geographical area for the clinic rather than making the comparison with figures for Canada as a whole. The Dalhousie clinic was chosen for this comparison, because this is the only clinic that could be assumed to provide all services for a single province. In the two other similar cases (UBC and Saskatoon), other services are provided by competing clinics. Even in the case of Dalhousie, the comparison is compromised, because patients may be referred from other Atlantic provinces.

Table 1.7(a) gives the raw numbers of infertile couples by occupation class, as well as the numbers for Canada, after adjusting the Canadian data for the age distribution of the infertile partners. Table 1.7(b) provides the Dalhousie and Nova Scotia comparison. In Table 1.8(a), the raw data are expressed in terms of the percentage of employed individuals, separated by sex, comparing infertile partners and the age-adjusted Canadian population; Table 1.8(b) provides this information for Dalhousie and Nova Scotia. In both comparisons, subtotals for the professions, services, and industrial and resources occupations suggest a small excess of infertile couples in the male professional group and a more notable excess in the

female professional group. Each category of the male professions is equally or slightly over-represented among the infertile couples. Among the female professions, the excess is explained almost completely by the greater number coming from the health professions, including nurses. The compensating decrease for this excess in the female professions is within the clerical group of female occupations.

Table 1.9 shows the distributions of occupations by socioeconomic index in the Canadian labour force, as described in detail by Blishen (1968). Although this scale was revised in 1976, we were unable to find revised cutpoints for the distributions; the cutpoints published in 1968 have therefore been used for this presentation. Also, we were unable to find quartile divisions and therefore used the Canadian distribution as reported by Blishen, shown in Table 1.9.

On the Blishen scale, lower occupations have higher numeric indices. Thus, the lowest socioeconomic stratum is represented by 50.00 or more and the highest by less than 30.00. The Canadian distribution in 1968, shown in the second column of Table 1.9, is not reflected in the infertile couples enrolled from 1984 to 1988 (CITES). Although the Blishen scale remains useful with respect to comparisons of individual occupations, it is no longer useful as a description of the distribution of occupations in Canada. Correlations between the Blishen ranking and male partners', female partners', and family income, as summarized in the paragraphs below, were as follows:

- Male partners' income and Blishen ranking: $r^2 = 0.058$, $p = 0.01$
- Female partners' income and Blishen ranking: $r^2 = 0.82$, $p = 0.01$
- Total family income and Blishen ranking: $r^2 = 0.046$, $p = 0.01$

Thus, although the Blishen ranking explains 82 percent of the variability in female partners' income in 1986 Canadian dollars, it explains less than 10 percent of the variability in male partners' or family income. Because the Blishen scale, at least as applied to our data, was less representative of the Canadian occupation distribution than the 1986 Canadian sub-census data, we have not presented analyses incorporating the Blishen scale in Sections 3 or 4.

Tables 1.10-1.12 compare the percent distribution of incomes in the Canadian data with the percent distribution in our sample. The quartiles are approximate, so that reasonable cutpoints in income could be used. For these three tables, we used only the Canadian data for the 25- to 34-year age group, which was then compared with those in our sample who were in the same age group. Among female infertile partners, only 30 percent (versus 48% for Canada) were in these categories (Table 1.11). When both partners' incomes are considered, family income distribution in the infertile group shifts slightly toward higher income categories (Table 1.12).

In addition to these comparisons, there are comparisons within our sample, denoted by the last two columns in Tables 1.10 and 1.11. These columns reflect the estimation of income among married males and

females, respectively, after we estimated the missing income data. These data were missing mainly because of the lack of occupational data from one clinic in the study. From postal code data available from the charts at that clinic, income was estimated for each partner. A comparison of the last two columns in each of Tables 1.10 and 1.11 would suggest that, particularly among the males, the income distribution calculated from non-missing cases is similar to that calculated with the use of postal code information. Thus, although we did not include couples with missing occupational data in any analyses that included socioeconomic variables, we feel confident that the missing cases are unlikely to be atypical.

Relationship Between Socioeconomic Status and Clinical Characteristics

Table 1.13, with its four sub-tables, illustrates the distribution of occupation-based socioeconomic status, arranged by infertility clinic, according to male occupation, female occupation, quartiles of the Blishen scale, and quartiles of total family income. In the last case, the quartiles are to the nearest thousand dollars. With respect to male occupation groups, one clinic accounted for more than three-quarters of the missing data. As noted above, data for this clinic were supplemented with the use of postal code information. Some of the interclinic differences with respect to occupation are notable: the high professional proportion in the Calgary and Ottawa clinics, and the high proportion of industrial and resources occupations in the Sherbrooke and Western Ontario clinics. While the Calgary and Ottawa clinics are in competition for referrals with other infertility clinics, both Sherbrooke and the University of Western Ontario provide regional service to large rural populations. With respect to family income, however, the interclinic differences are less impressive and the chi square is smaller (Table 1.13(4)).

We have made use of total family income as a simple summary estimate of occupational status; its distribution matches the Canadian distribution more closely than any other expression of occupation or socioeconomic status that we could find. As will be seen in the final section of this report, total family income contributes as much information to the prediction of pregnancy as any other expression of income or occupation. It therefore serves as the best single variable on which to categorize other clinical variables.

Clinical characteristics arranged by total family income are presented in Tables 1.14-1.18(a). In Tables 1.14-1.18(b), the clinical characteristics by total family income are provided for each centre. Missing data are treated separately, and statistics apply to the non-missing data.

Couples in the upper quartile of family income are older (both male and female partners), and they register in academic infertility clinics six months earlier in the course of their infertility than do couples with lower incomes (Tables 1.14(a) and (b)).

Couples in the upper income range were also more likely to have used contraception (both oral contraception and an intrauterine device) and to have coitus less frequently. Although they seemed more likely to have unexplained infertility, that trend was not significant. In other analyses, we have shown that female partners' age is the most important determinant of this diagnosis (Collins and Rowe 1989) (Tables 1.15(a) and (b)).

The primary clinical diagnosis, or most important diagnosis found in the infertile partnership when more than one diagnosis was present, is distributed reasonably evenly with respect to ovulation defects, seminal defects, and endometriosis. There is a trend, as noted in the previous table, to an increased frequency of unexplained infertility in the upper quartile of family income. The trend toward a higher frequency of tubal disease in the lower quartile of family income was significant ($p = 0.019$; Tables 1.16(a) and (b)).

With respect to procedures and outcomes, laparoscopy completion was most likely in the higher income group, but the trend to more frequent laparoscopy procedures with rising income was not significant (Tables 1.17(a) and (b)). This analysis, however, does not take into account the time to laparoscopy, and it includes those couples whose laparoscopy was performed prior to registration, a possibly confounding factor. Whether treatment was received was different among the family income groups, and the slight trend toward less treatment with higher income was marginally significant. With respect to pregnancy, a trend toward a higher pregnancy rate with higher income was significant by conventional standards ($p = 0.009$). Neither the amount of time a couple's progress was followed nor the interval from registration to the start of treatment was different among the family income groups. The distribution of loss to follow-up was skewed toward the lower family income, and the trend was significant (Tables 1.18(a) and (b)).

It has been suggested that centres should be included as covariates in the analysis of trends because of the magnitude of variation in family income among the centres. To test for the presence of confounding, the predicted beta coefficients were compared when a centre was entered as a covariate and when it was omitted. These analyses were carried out using linear regression for continuous variables: time observed, time to start of treatment, and female and male partners' ages; logistic regression was used for the rest of the variables in Table 1.19, which are all dichotomous. Dummy variables representing the second, third, and fourth quartiles of family income were created. The regression coefficients that were computed are: β_1 — below 25th percentile; β_2 — 26th-50th percentiles; β_3 — 51st-75th percentiles. The centre was included as an independent variable and the analysis repeated to estimate β_1 centre, β_2 centre, and β_3 centre. As can be seen from the estimates of the beta coefficients in Table 1.19, the effect of including coefficients representing the centres was small enough to justify the simpler analyses presented here.

Table 1.7(a) Number of Employed Infertile Partners and Age-Adjusted Numbers in Canada, by Occupation Class, 1986 Sub-Census

Occupations	Number of employed individuals			
	Male		Female	
	CITES	Canada	CITES	Canada
Professions				
management	215	784 382	77	357 290
science	128	406 631	24	85 778
social science	43	105 979	46	122 437
religion	9	15 891	1	2 703
teaching	69	179 385	120	255 353
health	47	124 563	246	410 666
arts, etc.	38	120 727	34	78 492
Subtotal	549	1 737 558	548	1 312 719
Services				
clerical	73	426 823	354	1 464 598
sales	140	531 333	125	335 961
services	123	550 200	137	585 450
Subtotal	336	1 508 356	616	2 386 009
Industry, resources				
farm, agriculture	48	236 382	10	71 603
fishing	21	36 855	0	3 482
forestry	13	80 365	1	5 349
mining	12	66 713	0	1 068
processing	68	314 143	14	81 602
machining	73	245 462	5	15 749
assembly, repair	144	684 013	38	163 627
construction	160	659 705	1	14 610
transportation	118	652 065	26	95 043
other	131	136 002	59	29 313
Subtotal	788	3 111 705	154	481 446
Total employed	1 673	6 357 619	1 318	4 180 174

Table 1.7(b) Number of Infertile Partners Attending the Infertility Centre at Dalhousie (DAL) and Age-Adjusted Numbers in Nova Scotia (N.S.), by Occupation Class, 1986 Sub-Census

Occupations	Number of employed individuals			
	Male		Female	
	DAL	N.S.	DAL	N.S.
Professions				
management	44	22 789	11	11 178
science	24	11 650	4	2 268
social science	11	2 972	8	4 068
religion	2	636	0	144
teaching	22	7 442	36	11 367
health	11	3 645	78	21 190
arts, etc.	9	3 177	4	2 107
Subtotal	123	52 311	141	52 322
Services				
clerical	21	12 713	88	55 548
sales	33	18 020	41	13 690
services	54	30 417	49	28 189
Subtotal	108	61 150	178	97 427
Industry, resources				
farm, agriculture	4	5 701	0	2 031
fishing	20	9 075	0	596
forestry	8	4 955	1	461
mining	8	3 469	0	45
processing	10	10 932	2	6 747
machining	16	6 223	1	367
assembly, repair	36	22 893	4	3 118
construction	52	32 665	0	462
transportation	37	24 915	8	2 825
other	41	5 707	17	1 188
Subtotal	232	126 535	33	17 840
Total employed	463	239 996	352	167 589

Table 1.8(a) Percent Distribution of Infertile Partners and Age-Adjusted Percentages in Canada, by Occupation Class, 1986 Sub-Census

Occupations	Percentage of employed individuals			
	Male		Female	
	CITES	Canada	CITES	Canada
Professions				
management	12.9	12.3	5.8	8.5
science	7.7	6.4	1.8	2.1
social science	2.6	1.7	3.5	2.9
religion	0.5	0.2	0.1	0.1
teaching	4.1	2.8	9.1	6.1
health	2.8	2.0	18.7	9.8
arts, etc.	2.3	1.9	2.6	1.9
Subtotal	32.8	27.3	41.6	31.4
Services				
clerical	4.4	6.7	26.9	35.0
sales	8.4	8.4	9.5	8.0
services	7.4	8.7	10.4	14.0
Subtotal	20.1	23.8	46.7	57.0
Industry, resources				
farm, agriculture	2.9	3.7	0.8	1.7
fishing	1.3	0.6	0.0	0.1
forestry	0.8	1.3	0.1	0.1
mining	0.7	1.0	0.0	0.0
processing	4.1	4.9	1.1	2.0
machining	4.4	3.9	0.4	0.4
assembly, repair	8.6	10.8	2.9	3.9
construction	9.6	10.4	0.1	0.3
transportation	7.1	10.3	2.0	2.3
other	7.8	2.1	4.5	0.7
Subtotal	47.1	48.9	11.7	11.6
Total employed	100.0	100.0	100.0	100.0

Table 1.8(b) Percent Distribution of Infertile Partners Attending the Infertility Centre at Dalhousie (DAL) and Age-Adjusted Percentages in Nova Scotia (N.S.), by Occupation Class, 1986 Sub-Census

Occupations	Percentage of employed individuals			
	Male		Female	
	DAL	N.S.	DAL	N.S.
Professions				
management	9.5	9.5	3.1	6.7
science	5.2	4.9	1.1	1.4
social science	2.4	1.2	2.3	2.4
religion	0.4	0.3	0.0	0.1
teaching	4.8	3.1	10.2	6.8
health	2.4	1.5	22.2	12.6
arts, etc.	1.9	1.3	1.1	1.3
Subtotal	26.6	21.8	40.0	31.2
Services				
clerical	4.5	5.3	25.0	33.1
sales	7.1	7.5	11.6	8.2
services	11.7	12.7	13.9	16.8
Subtotal	23.3	25.5	50.6	58.1
Industry, resources				
farm, agriculture	0.9	2.4	0.0	1.2
fishing	4.3	3.8	0.0	0.4
forestry	1.7	2.1	0.3	0.3
mining	1.7	1.4	0.0	0.0
processing	2.2	4.6	0.6	4.0
machining	3.5	2.6	0.3	0.2
assembly, repair	7.8	9.5	1.1	1.9
construction	11.2	13.6	0.0	0.3
transportation	8.0	10.4	2.3	1.7
other	8.9	2.4	4.8	0.7
Subtotal	50.1	52.8	9.4	10.7
Total employed	100.0	100.0	100.0	100.0

Table 1.9 Distribution of Occupations by Socioeconomic Index (SEI)* in the Canadian Labour Force, 1968, and in Academic Infertility Clinics in Canada, 1984-1988, (CITES)

Distribution of SEI	Percentage of occupations in Canada	Number of occupations in this range	CITES by couple** (%)
50.00 or more	17	36	40
40.00-49.99	20	52	19
30.00-39.99	32	103	19
less than 30.00	31	79	22

* Based on Blishen (1968).
 ** The higher occupational rating within each couple was used.

Table 1.10 Percent Distribution of Income Among Married Males by Income Group in Canada, Ages 25-34, and in Academic Infertility Clinics, 1984-88, (CITES)

Income group	Canada* (%)	CITES (n = 1 257) (%)	CITES** (n = 1 482) (%)
under \$20 000	26	10	9
\$20 000 - 29 999	27	50	53
\$30 000 - 39 999	26	35	34
\$40 000 and above	21	5	4
Total	100	100	100

* 1985 data, from Canada, Statistics Canada (1989b), Table 54.
 ** Estimates of missing male income from Canada, Statistics Canada (1990).

Table 1.11 Percent Distribution of Income Among Married Females by Income Group in Canada, 1985, Ages 25-34, and in Academic Infertility Clinics, 1984-88, (CITES)

Income group	Canada* (%)	CITES (n = 1 374) (%)	CITES** (n = 1 619) (%)
under \$6 000	24	26	22
\$6 000 - 11 999	24	4	9
\$12 000 - 19 999	27	44	47
\$20 000 and above	25	26	22
Total	100	100	100

* 1985 data, from Canada, Statistics Canada (1989b), Table 67.

** Estimates of missing female income from Canada, Statistics Canada (1989b).

Table 1.12 Percent Distribution of Families by Income Group (Married Male Head, Ages 25-34) in Canada, 1985, and in Academic Infertility Clinics, 1984-88, (CITES)

Income group	Canada* (%)	CITES (n = 1 257) (%)
Under \$30 000	35	19
\$30 000 - 39 000	26	21
\$40 000 - 49 999	19	30
\$50 000 and over	20	30
Total	100	100

* 1985 data from Canada, Statistics Canada (1989b) Table 8.

Table 1.13 Distribution of Occupation-Based Socioeconomic Status, Arranged by Infertility Clinic

(1) Male occupation groups

Infertility clinic	Professional (%)	Services (%)	Industrial (%)	Missing and unemployed (%)	Total number
Sherbrooke	19.5	16.5	57.1	6.8	133
Calgary	52.2	20.7	26.1	1.1	92
Dalhousie	26.0	22.8	49.0	2.1	473
Laval	21.1	17.5	50.9	10.5	114
Queen's	39.8	19.3	39.8	1.1	88
McMaster	14.5	7.7	26.5	51.3	729
Ottawa	51.4	15.1	28.6	4.9	185
McGill	41.3	21.7	28.3	8.7	92
UBC	29.2	14.6	23.6	32.6	89
UWO	19.8	22.4	51.7	6.0	116
Saskatoon	26.4	20.7	50.6	2.3	87
Total number	567	347	822	462	2 198
Overall percent	25.8	15.8	37.4	21.0	100.0
					χ^2 779.4 df 30 p < 0.00005

Table 1.13 (cont'd)

(2) Female occupation groups

Infertility clinic	Professional (%)	Services (%)	Industrial (%)	Missing and unemployed (%)	Total number
Sherbrooke	22.6	39.1	12.0	26.3	133
Calgary	37.0	38.0	7.6	17.4	92
Dalhousie	29.8	37.6	7.0	25.6	473
Laval	28.9	40.4	8.8	21.9	114
Queen's	42.0	28.4	12.5	17.0	88
McMaster	16.7	17.6	4.5	61.2	729
Ottawa	45.9	28.6	9.7	15.7	185
McGill	19.6	28.3	13.0	39.1	92
UBC	14.6	18.0	3.4	64.0	89
UWO	26.7	43.1	9.5	20.7	116
Saskatoon	39.1	34.5	5.7	20.7	87
Total number	578	639	159	822	2 198
Overall percent	26.3	29.1	7.2	37.4	100.0

χ^2 388.3

df 30

p < 0.00005

(3) Quartiles of Blishen socioeconomic scale

Infertility clinic	Upper (%)	Upper middle (%)	Lower middle (%)	Lower (%)	Total number
Sherbrooke	10.7	26.0	22.9	40.5	131
Calgary	34.8	41.3	15.2	8.7	92
Dalhousie	21.6	22.5	29.3	26.6	467
Laval	14.3	26.8	28.6	30.4	112
Queen's	25.0	29.5	23.9	21.6	88
McMaster	22.3	21.5	25.1	31.1	395
Ottawa	27.4	37.4	21.8	13.4	179
McGill	25.8	21.3	25.8	27.0	89
UBC	33.8	20.6	19.1	26.5	68
UWO	21.6	23.4	27.9	27.0	111
Saskatoon	24.4	29.1	20.9	25.6	86
Total number	413	469	457	479	1 818
Overall percent	22.7	25.8	25.1	26.3	χ^2 97.0 df 30 p < 0.00005

Table 1.13 (cont'd)
(4) Quartiles of total family income

Infertility clinic	Upper (%)	Upper middle (%)	Lower middle (%)	Lower (%)	Total number
Sherbrooke	35.3	30.8	24.1	9.8	133
Calgary	10.9	22.8	26.1	40.2	92
Dalhousie	26.9	27.8	21.8	23.5	467
Laval	28.6	29.5	25.0	17.0	112
Queen's	20.5	25.0	31.8	22.7	88
McMaster	23.9	25.5	26.1	24.5	326
Ottawa	14.4	20.6	26.1	38.9	180
McGill	35.9	26.1	19.6	18.5	92
UBC	36.8	27.9	16.2	19.1	68
UWO	18.8	32.1	31.3	17.9	112
Saskatoon	24.4	26.7	23.3	25.6	86
Total number	438	470	431	422	1 761
Overall percent	24.9	26.7	24.5	24.0	100.0
					χ^2 92.3 df 30 p < 0.00005

Table 1.14(a) Duration of Infertility and Age of the Female and Male Partners, Arranged by Total Family Income

Total family income quartile	Valid number	Duration of infertility (months)		Female partner's age (years)		Male partner's age (years)	
		Mean	S.D.	Mean	S.D.	Mean	S.D.
Lower	442	41.9	26.9	28.1	4.5	30.7	5.4
Lower middle	439	41.8	25.8	28.5	3.9	31.1	4.7
Upper middle	440	35.6	23.9	31.3	3.6	33.3	4.2
Upper	440	35.6	23.9	31.3	3.6	33.3	4.2
Missing	437	49.2	30.8	30.5	4.3	32.8	4.9
Total	2 198						
Overall mean, S.D.		41.9	27.2	29.5	4.2	31.9	4.8
Statistics for non-missing data							
F ratio		5.6		58.7		25.3	
p value		0.0006		< 0.00005		< 0.00005	
F for linearity		12.3		157.8		65.7	
p value		0.0005		< 0.00005		< 0.00005	

Table 1.14(b) Duration of Infertility and Age of the Female and Male Partners, Arranged by Infertility Centre and by Total Family Income

Infertility centre	Total family income quartile	Valid number	Duration of infertility (months)		Female partner's age (years)		Male partner's age (years)	
			Mean	S.D.	Mean	S.D.	Mean	S.D.
Sherbrooke	Lower	48	32.4	16.9	26.7	4.1	29.1	4.5
	Lower middle	39	29.7	15.3	26.7	3.0	29.1	4.3
	Upper middle	32	28.7	18.8	29.3	2.9	30.9	3.3
	Upper	14	32.7	17.2	29.2	3.7	31.6	3.8
	Total	133						
	Centre mean, S.D.		30.8	16.9	27.6	3.6	29.8	4.2
Calgary	Lower	10	29.6	16.2	26.0	3.9	27.2	3.2
	Lower middle	21	37.7	24.2	28.9	3.7	30.5	4.6
	Upper middle	23	41.7	20.7	28.7	3.6	29.2	3.3
	Upper	38	25.1	14.8	30.4	3.4	32.5	4.2
	Total	92						
	Centre mean, S.D.		32.6	20.0	29.1	3.8	30.6	4.3
Dalhousie	Lower	127	41.7	25.8	26.9	3.9	30.1	5.7
	Lower middle	123	42.3	25.8	28.3	3.7	31.1	5.3
	Upper middle	107	42.2	27.7	28.9	3.6	31.2	4.4
	Upper	115	37.4	23.7	31.1	3.4	33.0	4.0
	Missing	1						

Centre mean, S.D.		41.0	25.7	28.8	3.9	31.3	5.0
Laval	Lower	32	41.9	28.3	4.8	30.6	4.7
	Lower middle	31	41.4	30.7	4.2	31.4	4.6
	Upper middle	27	34.3	17.8	3.1	29.5	2.4
	Upper	22	42.3	28.8	4.2	32.6	3.5
	Missing	2	33.0	21.2	1.9	28.7	4.5
Total		114					
Centre mean, S.D.		39.9	26.7	29.3	4.2	30.9	4.1
Queen's	Lower	18	39.9	30.2	4.3	31.5	4.9
	Lower middle	20	41.5	27.7	4.6	31.1	4.1
	Upper middle	29	42.8	24.0	3.3	32.6	5.5
	Upper	21	36.2	27.0	3.2	34.2	4.0
Total		88					
Centre mean, S.D.		40.4	26.5	30.1	4.1	32.4	4.8
McMaster	Lower	80	49.8	31.1	4.0	31.8	4.8
	Lower middle	76	52.6	29.5	4.2	31.7	4.4
	Upper middle	88	48.3	29.4	3.6	32.2	4.9
	Upper	82	42.2	29.0	3.1	33.6	4.2
	Missing	403	49.8	30.8	4.3	32.9	4.9
Total		729					
Centre mean, S.D.		49.1	30.4	30.3	4.1	32.7	4.8

Table 1.14(b) (cont'd)

Infertility centre	Total family income quartile	Valid number	Duration of infertility (months)		Female partner's age (years)		Male partner's age (years)	
			Mean	S.D.	Mean	S.D.	Mean	S.D.
Ottawa	Lower	26	34.0	19.5	28.5	4.4	30.2	5.7
	Lower middle	34	35.8	23.8	28.0	3.0	30.8	4.4
	Upper middle	47	30.7	21.5	29.1	3.7	31.7	4.9
	Upper	73	25.5	14.1	31.8	3.2	34.1	4.3
	Missing	5	39.4	27.8	30.0	5.7	34.0	6.7
McGill	Total	185	30.3	19.6	29.9	3.9	32.3	5.0
	Centre mean, S.D.							
	Lower	33	41.4	31.4	28.6	5.4	31.9	6.2
	Lower middle	23	42.2	24.5	31.3	4.0	34.3	4.8
	Upper middle	19	35.9	42.6	31.3	5.6	33.9	6.7
UBC	Upper	17	32.0	20.8	32.1	3.8	33.8	4.8
	Total	92	38.7	30.7	30.5	5.0	33.3	5.8
	Centre mean, S.D.							
	Lower	25	40.8	24.9	31.8	3.8	33.9	5.1
	Lower middle	18	35.4	23.7	31.6	3.9	33.4	3.2
UBC	Upper middle	12	36.1	23.6	28.4	3.0	31.6	4.7
	Upper	13	33.3	27.8	31.6	5.1	32.0	3.4

Missing	21	43.0	55.3	31.3	4.1	32.9	4.4
Total	89						
Centre mean, S.D.		38.5	26.8	31.3	4.1	32.9	4.4
Lower	22	50.7	32.3	27.4	4.5	30.0	3.2
Lower middle	32	37.8	17.1	26.9	3.5	29.6	3.4
Upper middle	36	51.3	25.9	29.0	2.7	31.4	3.2
Upper	22	43.5	27.9	30.6	4.4	33.0	4.8
Missing	4	31.5	15.8	27.3	3.3	31.0	2.9
Total	116						
Centre mean, S.D.		45.3	25.7	28.4	3.9	30.9	3.7
Lower	21	44.1	23.7	26.7	6.0	30.3	7.2
Lower middle	22	47.4	25.4	27.2	2.8	30.4	4.5
Upper middle	20	43.1	20.8	28.5	2.7	31.5	4.7
Upper	23	44.7	19.4	31.9	4.9	32.9	4.8
Missing	1	72.0		25.4		31.0	
Total	87						
Centre mean, S.D.		45.2	22.2	28.6	4.7	31.3	5.4
Total	2 198						
Overall mean, S.D.		41.9	27.2	29.5	4.2	31.9	4.8

Table 1.15(a) Clinical Characteristics of Couples, Arranged by Total Family Income

Total family income quartile	Valid number	Previous oral contraceptive use (%)	Previous intrauterine device use (%)	Coitus less than twice per week (%)	Previous treatment of either partner (%)	Proportion with unexplained infertility (%)	Secondary infertility (%)
Lower	442	74.0	18.3	12.7	33.9	19.9	24.7
Lower middle	439	79.3	16.6	15.0	37.4	21.6	19.1
Upper middle	440	85.0	17.5	16.1	34.5	21.4	18.9
Upper	440	84.1	24.3	21.8	33.6	24.5	20.2
Missing	437	78.1	18.1	16.7	53.1	40.5	29.3
Total	2 198						
Overall percent		80.1	19.0	16.5	38.5	25.6	22.4
Statistics for non-missing data							
χ^2 3 df		21.4	10.0	14.1	1.68	2.9	5.7
p value		0.0001	0.019	0.003	0.64	0.41	0.13
χ^2 for trend 1 df		17.3	4.9	12.0	n.d.	2.4	2.5
p value		< 0.00005	0.028	0.0005		0.12	0.12

Table 1.15(b) Clinical Characteristics of Couples, Arranged by Infertility Centre and by Total Family Income

Infertility centre	Total family income quartile	Valid number	Previous oral contraceptive use (%)	Previous intrauterine device use (%)	Coitus less than twice per week (%)	Proportion with unexplained infertility (%)	Secondary infertility (%)
Sherbrooke	Lower	48	81.3	29.2	10.4	6.3	20.8
	Lower middle	39	84.6	15.4	15.4	10.3	25.6
	Upper middle	32	84.4	9.4	37.5	9.4	18.8
	Upper	14	78.6	28.6	57.1	28.6	21.4
	Total	133					
Calgary	Centre percentage		82.7	20.3	23.3	10.5	21.8
	Lower	10	90.0	0.0	30.0	30.0	20.0
	Lower middle	21	71.4	19.0	14.3	28.6	19.0
	Upper middle	23	91.3	13.0	8.7	26.1	17.4
	Upper	38	100.0	42.1	26.3	36.8	13.2
Dalhousie	Total	92					
	Centre percentage		90.2	25.0	19.6	31.5	16.3
	Lower	127	80.3	13.4	8.7	26.8	19.7
	Lower middle	123	86.2	16.3	11.4	33.3	17.1
	Upper middle	107	87.9	18.7	14.0	35.5	6.5
	Upper	115	84.3	19.1	15.7	39.1	26.1
	Missing	1	0.0	0.0	0.0	0.0	100.0
	Total	473					
	Centre percentage		84.4	16.7	12.3	33.4	17.8

Table 1.15(b) (cont'd)

Infertility centre	Total family income quartile	Valid number	Previous oral contraceptive use (%)	Previous intrauterine device use (%)	Coitus less than twice per week (%)	Proportion with unexplained infertility (%)	Secondary infertility (%)
Laval	Lower	32	71.9	15.6	6.3	15.6	37.5
	Lower middle	31	83.9	16.1	6.5	16.1	25.8
	Upper middle	27	85.2	33.3	7.4	7.4	40.7
	Upper	22	90.9	31.8	18.2	4.5	18.2
	Missing	2	100.0	0.0	0.0	50.0	50.0
Total		114					
Centre percentage			82.5	22.8	8.8	12.3	31.6
Queen's	Lower	18	83.3	16.7	11.1	16.7	33.3
	Lower middle	20	80.0	15.0	0.0	30.0	20.0
	Upper middle	29	96.6	6.9	17.2	24.1	34.5
	Upper	21	71.4	33.3	9.5	14.3	23.8
	Total	88					
Centre percentage			84.1	17.0	10.2	21.6	28.4
McMaster	Lower	80	63.8	12.5	15.0	17.5	26.3
	Lower middle	76	65.8	17.1	15.8	18.4	14.5
	Upper middle	88	73.9	14.8	18.2	17.0	23.9
	Upper	82	73.2	19.5	20.7	25.6	20.7
	Missing	403	77.2	18.9	17.1	41.7	28.8
Total		729					

		Centre percentage						
Ottawa	Lower	26	61.5	23.1	38.5	11.5	19.2	
	Lower middle	34	88.2	17.6	20.6	0.0	17.6	
	Upper middle	47	93.6	29.8	17.0	14.9	17.0	
	Upper	73	91.8	26.0	32.9	6.8	19.2	
	Missing	5	100.0	0.0	20.0	0.0	60.0	
	Total	185						
McGill	Centre percentage		87.6	24.3	27.0	8.1	19.5	
	Lower	33	48.5	12.1	12.1	21.2	24.2	
	Lower middle	23	56.5	13.0	30.4	30.4	34.8	
	Upper middle	19	78.9	5.3	26.3	15.8	21.1	
	Upper	17	76.5	23.5	5.9	11.8	29.4	
	Total	92						
UBC	Centre percentage		62.0	13.0	18.5	20.7	27.2	
	Lower	25	88.0	60.0	8.0	44.0	28.0	
	Lower middle	18	83.3	27.8	38.9	33.3	16.7	
	Upper middle	12	83.3	16.7	8.3	33.3	25.0	
	Upper	13	92.3	30.8	15.4	38.5	15.4	
	Missing	21	85.7	14.3	14.3	33.3	28.6	
	Total	89						
	Centre percentage		86.5	32.6	16.9	37.1	23.6	

Table 1.15(b) (cont'd)

Infertility centre	Total family income quartile	Valid number	Previous oral contraceptive use (%)	Previous intrauterine device use (%)	Coitus less than twice per week (%)	Proportion with unexplained infertility (%)	Secondary infertility (%)
UWO	Lower	22	86.4	9.1	13.6	13.6	40.9
	Lower middle	32	87.5	15.6	12.5	15.6	15.6
	Upper middle	36	83.3	19.4	8.3	22.2	16.7
	Upper	22	86.4	27.3	18.2	22.7	4.5
	Missing	4	100.0	0.0	0.0	25.0	25.0
	Total	116					
	Centre percentage		86.2	17.2	12.1	19.0	19.0
Saskatoon	Lower	21	71.4	23.8	9.5	9.5	19.0
	Lower middle	22	72.7	13.6	18.2	4.5	18.2
	Upper middle	20	85.0	15.0	10.0	5.0	15.0
	Upper	23	78.3	8.7	26.1	13.0	13.0
	Missing	1	100.0	0.0	0.0	0.0	0.0
	Total	87					
	Centre percentage		77.0	14.9	16.1	8.0	16.1
Total		2 198					
Overall percentage			80.1	19.0	16.5	25.6	22.4

Table 1.16(a) Primary Clinical Diagnosis (PCD), Arranged by Total Family Income

Total family income quartile	Valid number	PCD (%)				
		Ovulation	Unexplained	Seminal	Tubal	Endometriosis
Lower	442	19.9	19.9	27.8	25.6	5.7
Lower middle	439	23.7	21.6	23.0	22.6	7.3
Upper middle	440	20.9	21.4	26.4	21.4	8.6
Upper	440	19.8	24.5	26.6	19.1	7.3
Missing	437	12.1	40.5	15.6	27.2	4.3
Total	2 198					
Overall percentage		19.3	25.6	23.9	23.2	6.6
χ^2 3 df		2.7	3.1	3.5	5.9	2.7
p value		0.44	0.36	0.32	0.12	0.44
χ^2 for trend 1 df		0.3	2.1	0.03	5.5	1.3
p value		0.59	0.14	0.85	0.019	0.26

¹ A breakdown of this category is presented in Table 2.2.

Table 1.16(b) Primary Clinical Diagnosis (PCD), Arranged by Infertility Centre and by Total Family Income

Infertility centre	Total family income quartile	Valid number	PCD (%)					
			Ovulation	Unexplained	Seminal	Tubal	Endometriosis	Other
Sherbrooke	Lower	48	18.8	6.3	52.1	18.8	2.1	2.1
	Lower middle	39	30.8	10.3	43.6	10.3	0.0	5.1
	Upper middle	32	25.0	9.4	40.6	15.6	9.4	0.0
	Upper	14	14.3	28.6	14.3	21.4	14.3	7.1
	Total	133						
Calgary	Centre percentage		23.3	10.5	42.9	15.8	4.5	3.0
	Lower	10	10.0	30.0	30.0	20.0	10.0	0.0
	Lower middle	21	23.8	28.6	9.5	19.0	14.3	4.8
	Upper middle	23	13.0	26.1	17.4	21.7	17.4	4.3
	Upper	38	7.9	36.8	21.1	21.1	7.9	5.3
Dalhousie	Total	92						
	Centre percentage		13.0	31.5	18.5	20.7	12.0	4.3
	Lower	127	23.6	26.8	19.7	25.2	4.7	0.0
	Lower middle	123	23.6	33.3	13.8	25.2	3.3	0.8
	Upper middle	107	22.4	35.5	17.8	18.7	5.6	0.0
Laval	Upper	115	19.1	39.1	20.9	12.2	5.2	3.5
	Missing	1	0.0	0.0	0.0	100.0	0.0	0.0
	Total	473						
	Centre percentage		22.2	33.4	18.0	20.7	4.7	1.1
	Lower	32	18.8	15.6	9.4	34.4	18.8	3.1
	Lower middle	31	22.6	16.1	19.4	16.1	22.6	3.2
	Upper middle	27	18.5	7.4	18.5	18.5	33.3	3.7

	2	50.0	50.0	0.0	0.0	0.0	0.0
Missing							
Total	114						
Centre percentage		20.2	12.3	14.0	24.6	25.4	3.5
Queen's							
Lower	18	16.7	16.7	33.3	22.2	11.1	0.0
Lower middle	20	15.0	30.0	15.0	30.0	10.0	0.0
Upper middle	29	10.3	24.1	34.5	20.7	10.3	0.0
Upper	21	14.3	14.3	57.1	9.5	4.8	0.0
Total	88						
Centre percentage		13.6	21.6	35.2	20.5	9.1	0.0
McMaster							
Lower	80	18.8	17.5	26.3	33.8	2.5	1.3
Lower middle	76	21.1	18.4	19.7	32.9	7.9	0.0
Upper middle	88	19.3	17.0	26.1	26.1	9.1	2.3
Upper	82	19.5	25.6	26.8	22.0	6.1	0.0
Missing	403	11.7	41.7	13.9	28.0	4.5	0.2
Total	729						
Centre percentage		15.2	31.8	18.8	28.3	5.3	0.5
Ottawa							
Lower	26	26.9	11.5	38.5	11.5	11.5	0.0
Lower middle	34	32.4	0.0	44.1	20.6	2.9	0.0
Upper middle	47	36.2	14.9	21.3	25.5	2.1	0.0
Upper	73	39.7	6.8	24.7	24.7	4.1	0.0
Missing	5	40.0	0.0	40.0	0.0	20.0	0.0
Total	185						
Centre percentage		35.7	8.1	29.7	21.6	4.9	0.0

Table 1.16(b) (cont'd)

Infertility centre	Total family income quartile	Valid number	PCD (%)					
			Ovulation	Unexplained	Seminal	Tubal	Endometriosis	Other
McGill	Lower	33	18.2	21.2	21.2	33.3	0.0	6.1
	Lower middle	23	39.1	30.4	4.3	26.1	0.0	0.0
	Upper middle	19	26.3	15.8	36.8	10.5	5.3	5.3
	Upper	17	17.6	11.8	41.2	17.6	5.9	5.9
	Total	92						
UBC	Centre percentage		25.0	20.7	23.9	23.9	2.2	4.3
	Lower	25	8.0	44.0	28.0	20.0	0.0	0.0
	Lower middle	18	16.7	33.3	38.9	5.6	0.0	5.6
	Upper middle	12	8.3	33.3	33.3	25.0	0.0	0.0
	Upper	13	0.0	38.5	46.2	15.4	0.0	0.0
UWO	Missing	21	9.5	33.3	42.9	14.3	0.0	0.0
	Total	89						
	Centre percentage		9.0	37.1	37.1	15.7	0.0	1.1
	Lower	22	18.2	13.6	31.8	27.3	9.1	0.0
	Lower middle	32	15.6	15.6	31.3	21.9	15.6	0.0
Saskatoon	Upper middle	36	16.7	22.2	25.0	27.8	8.3	0.0
	Upper	22	9.1	22.7	31.8	13.6	13.6	9.1
	Missing	4	25.0	25.0	25.0	25.0	0.0	0.0
	Total	116						
	Centre percentage		15.5	19.0	29.3	23.3	11.2	1.7
Saskatoon	Lower	21	23.8	9.5	42.9	14.3	9.5	0.0

Upper	23	13.0	13.0	39.1	26.1	4.3	4.3
Missing	1	0.0	0.0	0.0	100.0	0.0	0.0
Total	87						
Centre percentage		17.2	8.0	43.7	18.4	8.0	4.6
Total	2 198						
Overall percentage		19.3	25.6	23.9	23.2	6.6	1.5

Table 1.17(a) Procedures and Outcomes, Arranged by Total Family Income							
Total family income quartile	Valid number	Laparoscopy completed (%)	Treatment received (%)	Number pregnant	Percentage pregnant		
Lower	442	55.9	60.2	159	36.0		
Lower middle	439	63.8	63.1	175	39.9		
Upper middle	440	63.4	58.2	186	42.3		
Upper	440	61.1	55.2	195	44.3		
Missing	437	70.5	64.8	151	34.6		
Total	2 198			866			
Overall percentage		62.9	60.3		39.4		
χ^2 3 df		8.9	6.0		7.1		
p value		0.03	0.1		0.07		
χ^2 for trend 1 df		2.0	3.6		6.8		
p value		0.16	0.06		0.009		

Table 1.17(b) Procedures and Outcomes, Arranged by Infertility Centre and by Total Family Income

Infertility centre	Total family income quartile	Valid number	Laparoscopy completed (%)	Treatment received (%)	Percentage pregnant
Sherbrooke	Lower	48	41.7	62.5	20.8
	Lower middle	39	20.5	51.3	43.6
	Upper middle	32	12.5	53.1	31.3
	Upper	14	42.9	50.0	50.0
	Total	133			
Calgary	Centre percentage		28.6	55.6	33.1
	Lower	10	60.0	50.0	20.0
	Lower middle	21	81.0	57.1	28.6
	Upper middle	23	73.9	34.8	30.4
	Upper	38	63.2	39.5	63.2
Dalhousie	Total	92			
	Centre percentage		69.6	43.5	42.4
	Lower	127	47.2	49.6	39.4
	Lower middle	123	69.1	58.5	40.7
	Upper middle	107	58.9	54.2	46.7
	Upper	115	51.3	40.9	44.3
	Missing	1			
	Total	473	100.0	100.0	0.0

Laval	Centre percentage		56.7	51.0	32.1
	Lower	32	78.1	78.1	25.0
	Lower middle	31	87.1	80.6	48.4
	Upper middle	27	81.5	81.5	51.9
	Upper	22	86.4	86.4	45.5
	Missing	2	50.0	50.0	0.0
	Total	114			
	Centre percentage		82.5	80.7	41.2
	Lower	18	100.0	50.0	38.9
	Lower middle	20	95.0	45.0	40.0
Queen's	Upper middle	29	86.2	34.5	34.5
	Upper	21	95.2	57.1	61.9
	Total	88			
	Centre percentage		93.2	45.5	43.2
	Lower	80	70.0	72.5	43.8
	Lower middle	76	73.7	73.7	42.1
	Upper middle	88	68.2	64.8	46.6
	Upper	82	67.1	76.8	42.7
	Missing	403	72.7	65.5	35.2
	Total	729			
McMaster	Centre percentage		71.3	68.3	39.1
	Lower	80	70.0	72.5	43.8
	Lower middle	76	73.7	73.7	42.1
	Upper middle	88	68.2	64.8	46.6
	Upper	82	67.1	76.8	42.7
	Missing	403	72.7	65.5	35.2
	Total	729			
	Centre percentage		71.3	68.3	39.1
	Lower	80	70.0	72.5	43.8
	Lower middle	76	73.7	73.7	42.1

Table 1.17(b) (cont'd)

Infertility centre	Total family income quartile	Valid number	Laparoscopy completed (%)	Treatment received (%)	Percentage pregnant
Ottawa	Lower	26	53.8	57.7	50.0
	Lower middle	34	50.0	61.8	50.0
	Upper middle	47	70.2	68.1	46.8
	Upper	73	56.2	49.3	38.4
	Missing	5	60.0	60.0	40.0
	Total	185			
	Centre percentage		58.4	59.1	44.3
McGill	Lower	33	30.3	51.5	36.4
	Lower middle	23	29.1	60.9	34.8
	Upper middle	19	42.1	26.3	42.1
	Upper	17	58.8	47.1	47.1
	Total	92			
	Centre percentage		40.2	47.8	39.1
UBC	Lower	25	48.0	60.0	28.0
	Lower middle	18	50.0	61.1	11.1
	Upper middle	12	75.0	66.7	16.7
	Upper	13	23.1	46.2	38.5

	Missing	21	28.6	52.4	28.6
	Total	89			
	Centre percentage		43.8	57.3	24.7
UWO	Lower	22	63.6	63.6	31.8
	Lower middle	32	68.8	62.5	21.9
	Upper middle	36	75.0	63.9	19.4
	Upper	22	72.7	63.6	36.4
	Missing	4	50.0	75.0	25.0
	Total	116			
	Centre percentage		69.8	63.8	25.9
Saskatoon	Lower	21	57.1	71.4	38.1
	Lower middle	22	50.0	77.3	59.1
	Upper middle	20	50.0	80.0	75.0
	Upper	23	65.2	69.6	26.1
	Missing	1	100.0	0.0	0.0
	Total	87			
	Centre percentage		56.3	73.6	48.3
Total		2 198			
	Overall percentage		62.8	60.3	39.4

Table 1.18(a) Time Under Observation in Clinic, Time from Registration to Start of Treatment, and Percentage of Couples Lost to Follow-up, Arranged by Total Family Income

Total family income quartile	Valid number	Observed time (months)		Time to treatment (months)		Lost to follow-up (%)
		Mean	S.D.	Mean	S.D.	
Lower	442	24.7	22.6	6.9	7.6	16.5
Lower middle	439	26.7	23.0	7.7	9.5	11.8
Upper middle	440	26.7	23.6	7.3	8.6	12.7
Upper	440	25.6	23.1	6.9	7.3	10.2
Missing	437	26.1	22.3	7.8	9.7	14.9
Total	2 198					
Overall mean, S.D.		26.0	22.9	7.4	8.6	
Overall percentage						13.2
Statistics for non-missing data						
F ratio		0.8		0.6		
p value		0.5		0.6		
F for linearity		0.26		0.5		
p value		0.6		0.4		
χ^2 3 df						8.4
p value						0.038
χ^2 for trend 1 df						6.4
p value						0.011

Table 1.18(b) Time Under Observation in Clinic, Time from Registration to Start of Treatment, and Percentage of Couples Lost to Follow-up, Arranged by Infertility Centre and by Total Family Income

Infertility centre	Total family income quartile	Valid number	Observed time (months)		Time to treatment (months)		Lost to follow-up (%)
			Mean	S.D.	Mean	S.D.	
Sherbrooke	Lower	48	16.3	8.2	5.8	4.7	31.3
	Lower middle	39	15.0	9.8	4.7	3.8	15.4
	Upper middle	32	13.2	7.5	7.0	4.9	21.9
	Upper	14	11.5	8.9	5.5	3.9	21.4
	Total	133					
	Centre mean, S.D.		14.7	8.7	5.7	4.4	23.3
Calgary	Centre percentage						
	Lower	10	19.2	18.2	13.6	3.7	60.0
	Lower middle	21	42.0	30.0	12.5	14.3	14.3
	Upper middle	23	37.2	33.1	11.3	7.8	17.4
	Upper	38	33.3	26.9	10.2	5.3	5.3
	Total	92					
Dalhousie	Centre mean, S.D.		34.7	28.8	11.5	9.0	16.3
	Centre percentage						
	Lower	127	31.9	28.2	7.2	8.2	10.2
	Lower middle	123	34.9	25.9	10.3	11.0	5.7
	Upper middle	107	33.5	26.6	10.4	13.5	7.5
	Upper	115	34.8	27.2	6.8	5.9	3.5

Table 1.18(b) (cont'd)

Infertility centre	Total family income quartile	Valid number	Observed time (months)		Time to treatment (months)		Lost to follow-up (%)
			Mean	S.D.	Mean	S.D.	
Dalhousie (cont'd)	Missing	1	25.3		4.7		100.0
	Total	473					
	Centre mean, S.D.		33.7	26.9	8.8	10.3	
	Centre percentage						7.0
Laval	Lower	32	24.4	13.4	3.3	3.8	18.8
	Lower middle	31	19.0	12.2	3.5	3.6	22.6
	Upper middle	27	17.7	13.0	3.8	4.5	18.5
	Upper	22	20.2	11.7	3.4	3.4	18.2
Queen's	Missing	2	27.4	13.3	0.5		50.0
	Total	114					
	Centre mean, S.D.		20.6	12.7	3.5	3.8	
	Centre percentage						20.2
McMaster	Lower	18	36.5	30.3	8.3	9.1	11.1
	Lower middle	20	38.0	33.9	17.0	15.1	10.0
	Upper middle	29	49.4	31.7	7.6	6.8	6.9
	Upper	21	28.1	24.4	10.0	4.4	4.8
McMaster	Total	88					
	Centre mean, S.D.		39.1	30.9	10.6	9.6	
	Centre percentage						8.0
McMaster	Lower	80	31.2	25.6	9.2	10.7	7.5
	Lower middle	76	30.7	22.8	6.8	8.7	5.3
	Upper middle	88	28.9	21.9	6.4	6.9	10.2

	Total	729								
	Centre mean, S.D.									
	Centre percentage									
	Lower	26	18.7	23.0	7.8	9.8				12.1
	Lower middle	34	22.5	21.1	9.9	13.0				11.5
	Upper middle	47	24.9	18.9	9.0	7.9				18.8
	Upper	73	20.8	21.6	6.8	5.7				14.3
	Missing	5	27.1	28.5	8.4	6.7				9.6
	Total	185								0.0
	Centre mean, S.D.									
	Centre percentage									
	Lower	33	12.3	10.1	7.9	5.6				8.1
	Lower middle	23	14.4	8.7	7.6	4.8				33.3
	Upper middle	19	12.1	8.6	5.8	1.7				30.4
	Upper	17	13.2	10.1	7.3	3.0				26.3
	Total	92								23.5
	Centre mean, S.D.									
	Centre percentage									
	Lower	25	16.6	8.8	5.7	3.8				29.3
	Lower middle	18	17.6	10.8	6.4	5.1				28.0
	Upper middle	12	19.7	12.8	3.8	2.8				27.8
	Upper	13	14.4	11.1	8.6	8.9				41.7
	Missing	21	15.8	9.0	5.1	3.1				30.8
	Total	89								33.3
	Centre mean, S.D.									
	Centre percentage									
	Lower	33	12.3	10.1	7.9	5.6				8.1
	Lower middle	23	14.4	8.7	7.6	4.8				33.3
	Upper middle	19	12.1	8.6	5.8	1.7				30.4
	Upper	17	13.2	10.1	7.3	3.0				26.3
	Total	92								23.5
	Centre mean, S.D.									
	Centre percentage									
	Lower	25	16.6	8.8	5.7	3.8				29.3
	Lower middle	18	17.6	10.8	6.4	5.1				28.0
	Upper middle	12	19.7	12.8	3.8	2.8				27.8
	Upper	13	14.4	11.1	8.6	8.9				41.7
	Missing	21	15.8	9.0	5.1	3.1				30.8
	Total	89								33.3
	Centre mean, S.D.									
	Centre percentage									
	Lower	33	12.3	10.1	7.9	5.6				8.1
	Lower middle	23	14.4	8.7	7.6	4.8				33.3
	Upper middle	19	12.1	8.6	5.8	1.7				30.4
	Upper	17	13.2	10.1	7.3	3.0				26.3
	Total	92								23.5
	Centre mean, S.D.									
	Centre percentage									
	Lower	25	16.6	8.8	5.7	3.8				29.3
	Lower middle	18	17.6	10.8	6.4	5.1				28.0
	Upper middle	12	19.7	12.8	3.8	2.8				27.8
	Upper	13	14.4	11.1	8.6	8.9				41.7
	Missing	21	15.8	9.0	5.1	3.1				30.8
	Total	89								33.3
	Centre mean, S.D.									
	Centre percentage									
	Lower	33	12.3	10.1	7.9	5.6				8.1
	Lower middle	23	14.4	8.7	7.6	4.8				33.3
	Upper middle	19	12.1	8.6	5.8	1.7				30.4
	Upper	17	13.2	10.1	7.3	3.0				26.3
	Total	92								23.5
	Centre mean, S.D.									
	Centre percentage									
	Lower	25	16.6	8.8	5.7	3.8				29.3
	Lower middle	18	17.6	10.8	6.4	5.1				28.0
	Upper middle	12	19.7	12.8	3.8	2.8				27.8
	Upper	13	14.4	11.1	8.6	8.9				41.7
	Missing	21	15.8	9.0	5.1	3.1				30.8
	Total	89								33.3
	Centre mean, S.D.									
	Centre percentage									
	Lower	33	12.3	10.1	7.9	5.6				8.1
	Lower middle	23	14.4	8.7	7.6	4.8				33.3
	Upper middle	19	12.1	8.6	5.8	1.7				30.4
	Upper	17	13.2	10.1	7.3	3.0				26.3
	Total	92								23.5
	Centre mean, S.D.									
	Centre percentage									
	Lower	25	16.6	8.8	5.7	3.8				29.3
	Lower middle	18	17.6	10.8	6.4	5.1				28.0
	Upper middle	12	19.7	12.8	3.8	2.8				27.8
	Upper	13	14.4	11.1	8.6	8.9				41.7
	Missing	21	15.8	9.0	5.1	3.1				30.8
	Total	89								33.3
	Centre mean, S.D.									
	Centre percentage									
	Lower	33	12.3	10.1	7.9	5.6				8.1
	Lower middle	23	14.4	8.7	7.6	4.8				33.3
	Upper middle	19	12.1	8.6	5.8	1.7				30.4
	Upper	17	13.2	10.1	7.3	3.0				26.3
	Total	92								23.5
	Centre mean, S.D.									
	Centre percentage									
	Lower	25	16.6	8.8	5.7	3.8				29.3
	Lower middle	18	17.6	10.8	6.4	5.1				28.0
	Upper middle	12	19.7	12.8	3.8	2.8				27.8
	Upper	13	14.4	11.1	8.6	8.9				41.7
	Missing	21	15.8	9.0	5.1	3.1				30.8
	Total	89								33.3
	Centre mean, S.D.									
	Centre percentage									
	Lower	33	12.3	10.1	7.9	5.6				8.1
	Lower middle	23	14.4	8.7	7.6	4.8				33.3
	Upper middle	19	12.1	8.6	5.8	1.7				30.4
	Upper	17	13.2	10.1	7.3	3.0				26.3
	Total	92								23.5
	Centre mean, S.D.									
	Centre percentage									
	Lower	25	16.6	8.8	5.7	3.8				29.3
	Lower middle	18	17.6	10.8	6.4	5.1				28.0
	Upper middle	12	19.7	12.8	3.8	2.8				27.8
	Upper	13	14.4	11.1	8.6	8.9				41.7
	Missing	21	15.8	9.0	5.1	3.1				30.8
	Total	89								33.3
	Centre mean, S.D.									
	Centre percentage									
	Lower	33	12.3	10.1	7.9	5.6				8.1
	Lower middle	23	14.4	8.7	7.6	4.8				33.3
	Upper middle	19	12.1	8.6	5.8	1.7				30.4
	Upper	17	13.2	10.1	7.3	3.0				26.3
	Total	92								23.5
	Centre mean, S.D.									
	Centre percentage									
	Lower	25	16.6	8.8	5.7	3.8				29.3
	Lower middle	18	17.6	10.8	6.4	5.1				28.0
	Upper middle	12	19.7	12.8	3.8	2.8				27.8
	Upper	13	14.4	11.1	8.6	8.9				41.7
	Missing	21	15.8	9.0	5.1	3.1				30.8
	Total	89								33.3
	Centre mean, S.D.									
	Centre percentage									
	Lower	33	12.3	10.1	7.9	5.6				8.1
	Lower middle	23	14.4	8.7	7.6	4.8				33.3
	Upper middle	19	12.1	8.6	5.8	1.7				30.4
	Upper	17	13.2	10.1	7.3	3.0				26.3
	Total	92								23.5
	Centre mean, S.D.									
	Centre percentage									
	Lower	25	16.6	8.8	5.7	3.8				29.3
	Lower middle	18	17.6	10.8	6.4	5.1				28.0
	Upper middle	12	19.7	12.8	3.8	2.8				27.8
	Upper	13	14.4	11.1	8.6	8.9				41.7
	Missing	21	15.8	9.0	5.1	3.1				30.8
	Total	89								33.3
	Centre mean, S.D.									
	Centre percentage									
	Lower	33	12.3	10.1	7.9	5.6				8.1
	Lower middle	23	14.4	8.7	7.6	4.8				33.3
	Upper middle	19	12.1	8.6	5.8	1.7				30.4
	Upper	17	13.2	10.1	7.3	3.0				26.3
	Total	92								23.5
	Centre mean, S.D.									
	Centre percentage									
	Lower	25	16.6	8.8	5.7	3.8				29.3
	Lower middle	18	17.6	10.8	6.4	5.1				28.0
	Upper middle	12	19.7	12.8	3.8	2.8				27.8
	Upper	13	14.4	11.1	8.6	8.9				41.7
	Missing	21	15.8	9.0	5.1	3.1				30.8
	Total	89								33.3
	Centre mean, S.D.									
	Centre percentage									
	Lower	33	12.3	10.1	7.9	5.6				8.1
	Lower middle	23	14.4	8.7	7.6	4.8				33.3
	Upper middle	19	12.1	8.6	5.8	1.7				30.4
	Upper	17	13.2	10.1	7.3	3.0				26.3
	Total	92								23.5
	Centre mean, S.D.									
	Centre percentage									
	Lower	25	16.6	8.8	5.7	3.8				29.3
	Lower middle	18	17.6	10.8	6.4	5.1				28.0
	Upper middle	12	19.7	12.8	3.8	2.8				27.8
	Upper	13	14.4	11.1	8.6	8.9				41.7
	Missing	21	15.8	9.0	5.1	3.1				30.8
	Total	89								33.3
	Centre mean, S.D.									
	Centre percentage									
	Lower	33	12.3	10.1	7.9	5.6				8.1
	Lower middle	23	14.4	8.7	7.6	4.8				33.3
	Upper middle	19	12.1	8.6	5.8	1.7				30.4
	Upper	17	13.2	10.1	7.3	3.0				26.3
	Total	92								23.5
	Centre mean, S.D.									
	Centre percentage									
	Lower	25	16.6	8.8	5.7	3.8				29.3
	Lower middle	18	17.6	10.8	6.4	5.1			</	

Table 1.18(b) (cont'd)

Infertility centre	Total family income quartile	Valid number	Observed time (months)		Time to treatment (months)		Lost to follow-up (%)
			Mean	S.D.	Mean	S.D.	
UWO	Lower	22	12.1	10.9	4.0	3.6	13.6
	Lower middle	32	14.5	9.1	3.2	1.6	21.9
	Upper middle	36	15.2	10.5	4.2	3.2	25.0
	Upper	22	12.6	8.3	5.0	2.2	9.1
	Missing	4	16.6	11.7	3.8	4.7	0.0
	Total	116					
Saskatoon	Centre mean, S.D.		14.0	9.8	4.0	2.8	
	Centre percentage						18.1
	Lower	21	19.1	15.1	5.9	7.4	4.8
	Lower middle	22	18.4	15.6	5.3	4.4	4.5
	Upper middle	20	13.4	9.9	6.1	4.6	0.0
	Upper	23	18.1	10.2	4.6	3.9	4.3
Total	Missing	1	6.7				0.0
	Total	87					
	Centre mean, S.D.		17.2	12.9	5.4	5.1	
	Centre percentage						3.4
	Overall mean, S.D.	2 198	26.0	22.9	7.4	8.6	
	Overall percentage						13.2

Table 1.19 Beta Coefficients for Total Family Income and Patient Characteristics With Infertility Centre and Without Infertility Centre as a Covariable

Dependent variable	β_1	β_1 centre	β_2	β_2 centre	β_3	β_3 centre
Oral contraceptive use	0.40	0.37	0.10	0.11	-0.28	-0.30
Intrauterine device use	0.046	0.046	0.164	0.165	0.102	0.092
LT2PERWK	-0.284	-0.281	-0.085	-0.07	-0.001	-0.003
Previous treatment	-0.041	-0.038	0.109	0.126	-0.014	-0.06
% unexplained diagnosis	-0.116	-0.153	-0.105	-0.028	-0.027	-0.005
Pregnancy history	0.231	0.211	-0.094	-0.098	-0.112	-0.119
PCD						
ovulation defect	-0.069	-0.050	-0.153	-0.179	-0.007	-0.002
seminal defect	0.098	0.083	-0.157	-0.167	0.024	-0.012
tubal defect	0.194	0.219	0.029	0.041	-0.041	-0.055
endometriosis	-0.248	-0.217	0.022	0.001	0.206	0.181
other defect ¹	-0.392	-0.487	0.092	0.041	-0.203	-0.167
Laparoscopy completed	-0.210	-0.13	0.119	0.17	0.094	0.04
Treated	0.048	0.045	0.092	0.09	-0.024	-0.037
Pregnant	-0.14	-0.14	-0.025	-0.02	0.023	0.03
Lost to follow-up	0.30	0.27	-0.02	-0.028	0.02	0.02
Time observed	-0.81	1.0	1.1	1.0	1.2	1.2
Time to start of treatment	-0.02	-0.12	0.8	0.7	0.41	0.40
Female partner's age	-3.2	-3.2	-2.8	-2.8	-1.98	-1.98
Male partner's age	-2.6	-2.6	-2.1	-2.1	-1.7	-1.8

¹ A breakdown of this category is presented in Table 2.2.

Section 3: The Effect of Clinical, Demographic, and Occupational Variables on Clinical Management (Table 1.20)

In this section, we present the final results of stepwise proportional hazards regression evaluating the contribution of clinical and demographic factors to diagnostic and treatment decisions among 1 761 infertile couples with non-missing data for total family income.

Laparoscopy is generally considered to be the benchmark of a complete investigation of infertility. Although the protocol for the study was not rigid, it would be reasonable to expect that laparoscopy would be carried out in a similar proportion of couples if the decision were based purely on the clinical indications. The 416 couples who had their laparoscopy performed prior to registration were excluded from this analysis so that we could make use of proportional hazards analysis, as time to laparoscopy was deemed to be important.

In the proportional hazards analysis, the strategy for selecting variables was to include clinical variables that were found to be important based on univariate analysis and multivariate stepwise logistic regression. Duration of infertility (DURATION), pregnancy history (PREGHIST), whether the female partner had been previously treated (FPREVTMT), and female partner's age (FEMAGE) were the patient characteristics that were to be included as covariates. Also included were dummy variables for the male professional occupations (MPRFESNL), male service occupations (MSERVICE), male industrial occupations (MNDUSTRL), and the respective female occupation variables. In addition, because laparoscopy is less likely with some treatments such as donor insemination where the diagnosis is already clear, we included a variable representing whether the couple received treatment as a time-dependent variable (XTIMERX). Also, laparoscopy would be less likely if a couple conceived, so a variable representing whether the couple conceived (PREGNANT) was added. Diagnostic variables were not entered into the equation for the likelihood of laparoscopy, because the final diagnosis in the majority of cases of infertility depends upon the completion of a laparoscopy. The analysis was stratified by treatment centre. The analysis was repeated on a subset of the data that included only couples from the four largest centres: Sherbrooke, Dalhousie, McMaster, and Ottawa.

Apart from the two treatment variables (these representing previous treatment of the female partner and treatment prescribed during the study observations), the duration of infertility was the only clinical variable that was significantly associated with the individual decision to have a laparoscopy. Table 1.20(a) presents the results of the analysis with all centres included. Laparoscopy was about 0.5 percent ($p = 0.0009$) more likely with each additional month of infertility (or about 6% per year) prior to registration (DURATION) and more than 32 percent ($p = 0.0001$) less likely

if the female partner had already received treatment prior to registration (such treatment usually being based on a diagnosis not requiring laparoscopy, such as azoospermia). Laparoscopy was less than half as likely (44%) ($p < 0.0005$) among those receiving early treatment, probably because a cause for the infertility had already been found in some other way. Most important, the laparoscopy decision was not affected by family income.

Table 1.20(b) shows the results of a proportional hazards analysis on time to treatment in the four clinics with the largest enrolments. The effect of duration of infertility was similar in this analysis. This analysis also shows that physician preferences, clinic policies, or other unknown factors underlie significant differences among the clinics. Compared with the three other clinics, laparoscopy was less than half as likely ($p < 0.0005$) at Sherbrooke. This result would be expected on the basis of the data in Table 1.6 (laparoscopy completion: Ottawa, 60%; Sherbrooke, 29%; Dalhousie, 57%; McMaster, 72%). The analysis adjusts for duration of infertility, however, which is shorter in Ottawa and Sherbrooke (30.3 and 30.8) than at McMaster (49.1 months at enrolment). Also, compared to any other occupational group, female professionals had a 22 percent ($p = 0.034$) lower likelihood of having a laparoscopy performed after enrolment. This probably reflects earlier laparoscopy (before enrolment) among this group, which included nurses and female physicians. Our analysis excluded all couples who had had prior laparoscopy.

Table 1.20(c) shows the clinical and demographic factors affecting treatment decisions among 1 761 infertile couples with non-missing information on occupation. Previous analyses as well as clinical judgment showed that a larger group of variables needed to be entered into this equation; thus income is the only occupation variable. Because treatment depends in large part on the diagnosis, we entered variables for ovulation defect, male defect, tubal defect, and endometriosis. Because treatment is more likely if pregnancy does not occur, the analysis was stratified by pregnancy (PREGNANT). Also included in the list of variables available to the model were the duration of infertility, pregnancy history, female partner's age, income, and a variable representing previous treatment of the female partner (FPREVTMT).

Treatment was approximately twice as likely with the diagnosis of an ovulation deficiency ($p < 0.0005$), 74 percent ($p < 0.0005$) more likely with endometriosis, and 25 percent ($p = 0.0033$) more likely with a diagnosis of a male defect. The duration of infertility was not a significant predictor of treatment.

As would be expected, where the female had received previous treatment, the likelihood of treatment was 14 percent ($p = 0.023$) lower. The most appropriate treatments may have been done by gynaecologists prior to referral to an infertility clinic. We can only surmise as to whether this explanation is appropriate; many couples were referred by gynaecologists and other physicians who were capable of carrying out such indicated treatment. Couples with such obvious diagnoses as ovulation disorders

may have completed one or more treatments prior to attending an academic infertility clinic. Furthermore, the referrals to clinics with IVF programs usually included treated couples with persistent infertility (frequently as a result of tubal disease).

Table 1.20(d) shows the same analysis among 1 111 couples from the four largest clinics. With Ottawa as the comparison centre, treatment was not significantly more likely at the Dalhousie or Sherbrooke clinics. At the McMaster clinic, however, after taking other likely factors into account, treatment was 77 percent ($p < 0.0005$) more likely.

The differences in diagnostic and treatment rates among the centres suggest that with infertility, as in other areas of clinical decision making, studies are needed to elucidate physician, patient, and additional factors that may affect diagnostic and treatment decisions. It is notable, however, that no occupational or income variables influenced either the decision to perform a laparoscopy or the decision to commence treatment.

Table 1.20(a) Clinical and Demographic Factors Affecting Laparoscopy Decisions Among 1 345 Infertile Couples: A Stepwise Proportional Hazards Analysis¹

Final model:

Variable	Relative hazard	Significance level
DURATION	1.0051	0.0009
FPREVTMT	0.6750	0.0001
Time to treatment	0.4417	< 0.0005

Variables not in the final model and the significance levels necessary for their entry:

Variable	Significance level to enter
PREGHIST	0.6113
*MPRFESNL	0.4042
*MSERVICE	0.2302
*MNDUSTRL	0.7572
*FPRFESNL	0.4256
*FSERVICE	0.1038
*FNDUSTRL	0.4174
FEMAGE	0.9728
PREGNANT	0.6524
*INCOME	0.3185

* occupational variables

¹ This analysis excludes couples whose laparoscopy was done prior to registration. The analysis is stratified by centre.

Table 1.20(b) Clinical and Demographic Factors Affecting Laparoscopy Decisions Among 828 Infertile Couples Attending Sherbrooke, Dalhousie, McMaster, and Ottawa Infertility Clinics: A Stepwise Proportional Hazards Analysis¹

Final model:

Variable	Relative hazard	Significance level
Sherbrooke	0.4866	0.0001
Time to treatment	0.5158	< 0.0005
FPREVTMT	0.6333	0.0004
PREGNANT	1.2683	0.0334
*FPRFESNL	0.7805	0.0336

Variables not in the final model and the significance levels necessary for their entry:

Variable	Significance level to enter
DURATION	0.3156
PREGHIST	0.8784
*MPRFESNL	0.3432
*MSERVICE	0.1967
*MNDUSTRL	0.7771
*FSERVICE	0.3728
*FNDUSTRL	0.5898
FEMAGE	0.2001
*INCOME	0.2055
Dalhousie	0.7453
McMaster	0.1225

* occupational variables

¹ This analysis excludes 283 couples whose laparoscopy was done prior to registration.

Table 1.20(c) Clinical and Demographic Factors Affecting Treatment Decisions: A Stepwise Proportional Hazards Analysis¹

Final model:

Variable	Relative hazard	Significance level
Ovulation defect	2.1184	< 0.0005
Endometriosis	1.7415	< 0.0005
Male defect	1.2548	0.0033
FEMAGE	0.9756	0.0023
FPREVTMT	0.8555	0.0232

Variables not in the final model and the significance levels necessary for their entry:

Variable	Significance level to enter
DURATION	0.8972
PREGHIST	0.7713
Tubal defect	0.5146
*INCOME	0.2161

* occupational variable

¹ This analysis was stratified by pregnant status.

Table 1.20(d) Clinical and Demographic Factors Affecting Treatment Decisions Among 1 111 Infertile Couples Attending Sherbrooke, McMaster, Dalhousie and Ottawa Infertility Clinics: A Stepwise Proportional Hazards Analysis¹

Final model:

Variable	Relative hazard	Significance level
Ovulation defect	2.3979	< 0.0005
McMaster	1.7681	< 0.0005
Endometriosis	1.4601	0.0006
DURATION	0.9952	0.0019
Male defect	1.2369	0.0292

Table 1.20(d) (cont'd)

Variables not in the final model and the significance levels necessary for their entry:

Variable	Significance level to enter
PREGHIST	0.3557
Tubal defect	0.8669
FEMAGE	0.9730
FPREVTMT	0.4955
Sherbrooke	0.2107
Dalhousie	0.5880
*INCOME	0.3383

* occupational variable

¹ This analysis was stratified by pregnant status.

Section 4: Clinical, Demographic, and Occupational Variables and the Outcome of Infertility (Tables 1.21-1.26)

The tables in this section relate to clinical, demographic, and occupational variables and the various outcomes that were observed among infertile couples: pregnancy, live birth, loss to follow-up, adoption, and resolution. Resolution was defined as a discontinued interest in infertility treatment during follow-up, an outcome distinct from loss to follow-up, where the couple simply failed to turn up without indicating their future wishes.

Table 1.21(a) is the first of several stepwise proportional hazards analyses with respect to pregnancy. It shows male occupation and clinical predictors of pregnancy among 1 773 infertile couples with non-missing information on male occupation. Each of the clinical variables (pregnancy history, coital frequency, duration of infertility, female age, and diagnoses) has been entered on the basis of previous univariate and multivariate stepwise logistic regressions identifying them as the significant clinical variables. In these analyses, the binary variables for duration of infertility (36 months cutpoint) and female partner's age (30 years cutpoint) were used to obtain a relative risk. The effects of these variables are discussed below. The time-dependent treatment and time-dependent laparoscopy variables were entered in order to control the effects of these two events, which are important with respect to pregnancy. The analyses were

stratified by centre. Where the male partner was in the professional category, the couple had a 36 percent ($p = 0.0003$) increased likelihood of pregnancy.

Table 1.21(b) provides similar information with respect to female occupation. As with the male professional category in the previous analysis, the female professional category also was significantly associated with a higher likelihood of pregnancy.

Table 1.22 shows the contribution of family income (expressed in tens of thousands of dollars) to the proportional hazards analysis model. Although the family income variable did not improve the predictor model significantly, the exponential (1.06) was significant ($p = 0.014$). This means that, for a \$10 000 increase in family income above the mean (\$43 400), there is a 6 percent increase in the likelihood of pregnancy. (Note: the occupation variable based on the Blishen socioeconomic index was not included in analyses with respect to the prediction of pregnancy, for reasons outlined in Section 2.)

In all of these analyses, the clinical predictors of pregnancy (duration of infertility, female partner's age, pregnancy history, and coital frequency) and the diagnostic predictors (ovulation defect, tubal defect, endometriosis, and male defect) reveal consistent relationships with pregnancy with respect to the magnitude of the coefficient and its significance. The likelihood of pregnancy is approximately 50 percent higher ($p < 0.0005$) with shorter duration of infertility or secondary infertility, 20 percent lower ($p = 0.0416$) with infrequent coitus, and 37 percent higher ($p = 0.0001$) with younger female partner's age. Compared with the criterion group (unexplained infertility), any other infertility diagnosis is associated with a lower probability of pregnancy, even after taking prescribed treatment into account. The impaired prognosis was significant with tubal defect (41% lower, $p < 0.0005$), endometriosis (also 41% lower, $p < 0.0005$), and male defect (18% lower, $p = 0.046$).

After the effects on pregnancy of clinical factors, occupation, and income were evaluated, the general purpose of the next set of analyses was to evaluate the clinical factors together with a representative socioeconomic variable, family income, with respect to their relation to the other infertility outcomes: live birth, loss to follow-up, adoption, and the decision to discontinue infertility investigation or therapy (resolution).

The proportional hazards analysis of patients' clinical characteristics in the prediction of live birth is presented in Table 1.23. The effect of patient factors was similar: live birth was 38 percent ($p = 0.0023$) more likely among those with a previous pregnancy and 50 percent more likely ($p < 0.00005$) with a shorter duration of infertility. Live birth was half as likely ($p < 0.0005$) in the presence of tubal defect; with endometriosis, the likelihood of live birth was reduced to 64 percent ($p = 0.0002$). The level of family income was not significantly associated with this outcome, suggesting that couples with higher incomes report pregnancy earlier (Table 1.22),

when spontaneous abortion (the major factor accounting for the difference between all pregnancies and live births) is more likely.

Table 1.24 shows a proportional hazards analysis of the clinical characteristics that could influence the likelihood of becoming lost to follow-up. The diagnosis of a tubal defect or endometriosis contributed significantly to the couple being lost to follow-up. The level of family income was not associated with this outcome, in contrast to the univariate analysis (Table 1.18(a)), thus indicating that the relationship between tubal disease, family income, and loss to follow-up may be complex.

The likelihood of adoption was also analyzed with the proportional hazards model; the results are shown in Table 1.25. The proportion of couples who adopted was only 6 percent, but the results showed that the likelihood of adoption improved by about 12 percent ($p = 0.039$) for each \$10 000 increase in family income. Those with a longer duration of infertility, a male defect or earlier treatment were also more likely to adopt. No other factor predicted the likelihood of adoption.

The effect of clinical factors on the likelihood that the couple will decide not to pursue further infertility investigations or treatment was analyzed with the proportional hazards model. As Table 1.26 shows, except for the diagnosis of a male defect, none of the other clinical characteristics or income contributed significantly to the likelihood of this outcome.

Table 1.21(a) Male Occupation and Other Clinical Predictors of Pregnancy Among 1 773 Infertile Couples: A Stepwise Proportional Hazards Analysis¹

Final model:

Variable	Relative hazard	Significance level
DURATION \leq 36 months	1.5545	< 0.0005
FEMAGE \leq 30 years	1.4056	0.0005
Tubal defect	0.5694	< 0.0005
Time to treatment	1.4795	< 0.0005
Endometriosis	0.5767	< 0.0005
PREGHIST	1.3935	0.0003
*MPRFESNL	1.3612	0.0003
LT2PERWK	0.7477	0.0070
Male defect	0.8039	0.0251

Table 1.21(a) (cont'd)

Variables not in the final model and the significance levels necessary for their entry:

Variable	Significance level to enter
Ovulation defect	0.8875
*MSERVICE	0.6398
*MNDUSTRL	0.8930
Time to laparoscopy	0.5594

* occupational variables

¹ This analysis was stratified by centre.

Table 1.21(b) Female Occupation and Other Clinical Predictors of Pregnancy Among 1 726 Infertile Couples: A Stepwise Proportional Hazards Analysis¹

Final model:

Variable	Relative hazard	Significance level
DURATION ≤ 36 months	1.5529	< 0.0005
FEMAGE ≤ 30 years	1.3667	0.0002
Tubal defect	0.5584	< 0.0005
Time to treatment	1.5242	< 0.0005
Endometriosis	0.5856	< 0.0005
PREGHIST	1.4590	0.0001
*FPRFESNL	1.2233	0.0154
LT2PERWK	0.7599	0.0131
Male defect	0.8277	0.0560

Variables not in the final model and the significance levels necessary for their entry:

Variable	Significance level to enter
Ovulation defect	0.8778
*FSERVICE	0.5926
*FNDUSTRL	0.8858
Time to laparoscopy	0.3097

* occupational variables

¹ This analysis was stratified by centre.

Table 1.22 Family Income and Other Clinical Predictors of Pregnancy Among 1 761 Infertile Couples: A Stepwise Proportional Hazards Analysis¹

Final model:

Variable	Relative hazard	Significance level
DURATION \leq 36 months	1.5281	< 0.0005
FEMAGE \leq 30 years	1.3729	0.0001
Tubal defect	0.5893	< 0.0005
Time to treatment	1.5056	< 0.0005
Endometriosis	0.5899	< 0.0005
PREGHIST	1.4624	< 0.0005
*INCOME	1.0621	0.0144
LT2PERWK	0.8024	0.0416
Male defect	0.8244	0.0456

Variables not in the final model and the significance levels necessary for their entry:

Variable	Significance level to enter
Ovulation defect	0.7622
Time to laparoscopy	0.3674

* occupational variable

¹ This analysis was stratified by centre.

Table 1.23 Clinical Characteristics and the Prediction of Live Birth Among Couples Attending Academic Infertility Clinics in Canada: A Stepwise Proportional Hazards Analysis¹

Final model:

Variable	Relative hazard	Significance level
DURATION \leq 36 months	1.4961	< 0.00005
FEMAGE \leq 30 years	1.3364	0.0014
Tubal defect	0.5043	< 0.00005
Time to treatment	1.5639	< 0.00005
Endometriosis	0.6377	0.0002
PREGHIST	1.3793	0.0023

Table 1.23 (cont'd)

Variables not in the final model and the significance levels necessary for their entry:

Variable	Significance level to enter
LT2PERWK	0.4076
Male defect	0.3672
Ovulation defect	0.4876
*INCOME	0.1253
Time to laparoscopy	0.2831

* occupational variable

¹ This analysis was stratified by centre.

Table 1.24 Clinical Characteristics and the Prediction of Loss to Follow-up Among Couples Attending Academic Infertility Clinics in Canada: A Stepwise Proportional Hazards Analysis¹

Final model:

Variable	Relative hazard	Significance level
DURATION ≤ 36 months	0.7665	0.0564
Tubal defect	0.6466	0.0051
Time to treatment	0.6187	< 0.0005
Endometriosis	0.6633	0.0348

Variables not in the final model and the significance levels necessary for their entry:

Variable	Significance level to enter
FEMAGE ≤ 30 years	0.9467
PREGHIST	0.1767
LT2PERWK	0.3427
Male defect	0.2509
Ovulation defect	0.6995
*INCOME	0.3124
Time to laparoscopy	0.7568

* occupational variable

¹ This analysis was stratified by centre.

Table 1.25 Clinical Characteristics and the Prediction of Adoption Among Infertile Couples Attending Academic Infertility Clinics in Canada: A Stepwise Proportional Hazards Analysis¹

Final model:

Variable	Relative hazard	Significance level
DURATION ≤ 36 months	0.6679	0.0352
Time to treatment	1.5911	0.0240
*INCOME	1.1249	0.0387
Male defect	1.4573	0.0867

Variables not in the final model and the significance levels necessary for their entry:

Variable	Significance level to enter
FEMAGE ≤ 30 years	0.4793
Tubal defect	0.7514
Endometriosis	0.5316
PREGHIST	0.5689
LT2PERWK	0.8945
Ovulation defect	0.1732
Time to laparoscopy	0.3917

* occupational variable

¹ Because of the low frequency of adoption, this analysis was not stratified by centre.

Table 1.26 Clinical Characteristics and the Likelihood of Discontinued Interest in Infertility Treatment and Follow-up Among Infertile Couples Attending Academic Infertility Clinics in Canada: A Stepwise Proportional Hazards Analysis¹

Final model:

Variable	Relative hazard	Significance level
Time to treatment	0.5488	< 0.00005
Male defect	1.3658	0.0504

Table 1.26 (*cont'd*)

Variables not in the final model and the significance levels necessary for their entry:

Variable	Significance level to enter
DURATION ≤ 36 months	0.6416
FEMAGE ≤ 30 years	0.6392
Tubal defect	0.2300
Endometriosis	0.2987
PREGHIST	0.6662
*INCOME	0.6420
LT2PERWK	0.5475
Ovulation defect	0.7633
Time to laparoscopy	0.1653

* occupational variable

¹ This analysis was stratified by centre.

Report 2: Report on the Proposal to Use the Cox Proportional Hazards Model to Study the Effect of Important Treatments on Pregnancy Among Infertile Couples

Background

Medical practice is more successful and more satisfying when rational, effective therapy is available to correct specific defects and lead to a desirable outcome. With respect to infertility, when the diagnosis is ovulation defect, seminal defect, adnexal disease, or uterine/cervical defect, standard treatments are indicated. With unexplained infertility, however, a specific defect is not present and so there is no rationale for therapy. Furthermore, the effectiveness of any given therapy is uncertain, in part because pregnancy occurs independently of treatment in some couples, and in part because of the lack of well-designed evaluation studies.

There is internal and external pressure for the couple to have treatment during a period of infertility. For many infertile couples, it is important to feel that they have done everything possible before deciding finally to discontinue investigations and unsuccessful therapy. The result of such influences will be different from couple to couple. Therefore, the

clinician must go beyond the usual issues associated with a recommendation for indicated therapy to consider how the natural history and prognosis, the couple's wishes and feelings, and the likely effectiveness of treatment may affect treatment decisions for the individual couple.

In many respects, infertility is similar to a chronic disease. The intensity of the disorder may wax or wane (spontaneous remission, in this instance resulting in pregnancy, may occur); there is no guaranteed cure; and those with the condition may educate themselves and become partners in their health care. Once the diagnosis has been established, the couple, acting on information provided by the physician, must make a series of decisions. In very general terms, these involve choices between treatment and no treatment, choices among treatment options if treatment is chosen, choices of continuing or discontinuing an individual treatment, and continuing or discontinuing treatment altogether. The physician must also constantly make decisions, the most important of which is choosing which treatment options to discuss.

The decision-making process is composed of factors that influence the physician and those that influence the patient. For physicians, clinical decisions may be influenced by various factors: age, type of practice, sources of prescribing information, and the number of professional journals read, as well as influential clinical authorities. Thus, the physician may work with a perception of what peers would do in this circumstance together with a concept of what the patient's needs may be.

The perception of patients' attitudes is a further important component of the clinical decision-making process. Couples with infertility have a generally increased awareness of treatment options, which is a benefit arising from the greater public interest in health. This means that to a greater extent than ever before, clinical decisions can be tailored to the needs of the individual. Patients' feelings about infertility treatment, too, are influenced by age; this is particularly true of women who perceive that they have a limited time in which to conceive. Distance to be travelled, flexibility of daily home and work schedules, and the cost of treatment are additional factors specific to each patient. Patients also differ in their attitudes toward making decisions and taking risks. Finally, the influence of the media, friends, and relatives on a couple's decisions cannot be ignored. Given all these influences, it is not surprising that treatment rates differ among centres, as shown in Report 1, Section 3.

The factors that contributed to the treatment decision with regard to any treatment were considered in Report 1, Section 3. This report evaluates specific treatment decisions and presents an evaluation of the effect of these treatments among couples attending infertility clinics associated with medical schools in Canada.

Methods

The methods in this section are similar to those applied in Report 1. The following list of treatment variables was shown in Report 1, Section 1 — “F. Treatment Variables”:

1. any type of recognized infertility treatment, including clomiphene, surgery, artificial insemination, IVF, Danazol[®], Pergonal[®], etc. (Tables 2.1 and 2.2 give the complete list);
2. time to treatment (TIMETORX, XTIMERX) — the number of months from the time of registration to the date that the first treatment (clomiphene, surgery, IVF, etc.) was started. There are also time variables to measure the time from registration to the starting date of a second, third, etc. treatment;
3. time on treatment — the number of months (or cycles) from the time a treatment was started to the time the treatment was stopped.

Treatments for Infertility

Information was collected on the specific types of infertility treatment, when and for how long each was administered, and the event of pregnancy and outcome of the pregnancy. Table 2.1 lists the type, frequency, and order of treatments administered to 1 325 couples in the total group of 2 198 couples. Couples had up to eight treatments, but in some cases this includes repeated attempts with the same treatment. For example, if a woman received Clomid[®] for six months while the couple was on the IVF waiting list, then had four IVF treatments in the next year, this would be counted as five treatments.

To permit comparison with other types of treatment, there are several ways to handle IVF treatment times, none of which is entirely satisfactory. If the first cycle of IVF is used as the start date and the last cycle as the finishing date, the drawback is that other treatments may occur after an IVF cycle is completed. A second approach counts only the cycle in which IVF is done as the treatment cycle and each IVF attempt as an independent treatment. The drawback here is that proportional hazards may exaggerate the benefit of such treatment because, if effective, the treatment time is extremely short. The third approach compensates for that weakness by assigning three months as each IVF cycle time, a choice that is consistent with clinical practice. This last approach is the one used in the proportional hazards analyses in this report.

Table 2.1 shows that clomiphene, surgery, therapeutic donor insemination (TDI), and IVF (or GIFT) were the treatments used most frequently. The treatments used less frequently were combined into the “other” category; a breakdown of this category is presented in Table 2.2.

When couples have had the most appropriate treatment for their infertility, or when no treatment is reasonable for such problems as severe

tubal obstruction, they are likely to register on the waiting list for IVF. Many couples ask for further treatment while waiting one to three years for IVF, in the hope that the expense of IVF will not be necessary. Treatment in such circumstances is offered in the hope that it will augment normal mechanisms of fertilization. Such treatments include ovulation induction in women who have normal ovulation, intrauterine insemination (IUI) when the male partner has normal semen, or bromocriptine in women with normal prolactin concentrations. Superovulation treatment can, theoretically, enhance fertilization by increasing the yield of oocytes or by correcting unrecognized ovulatory dysfunction among apparently ovulatory infertile women. IUI of sperm separated from seminal plasma may increase the number of sperm reaching the ampulla of the fallopian tube. Couples who chose augmentation therapy were similar to other couples with respect to infertility duration, occupation group, male partner's age, and pregnancy history; the female partners were significantly older, however, than in other treated couples ($p = 0.0003$), and more couples were in the unexplained diagnosis group.

For each important treatment, Table 2.3 shows how long (in months) after registration treatment was started and the length of time it was used. Each treatment is also categorized according to whether it was used to treat a specific disorder or in the absence of the related infertility disorder (augmentation therapy). Most treatments were prescribed within six to nine months of registration, but IVF was started an average of 18 months after registration, most likely because of a combination of such factors as cost, waiting lists, and side-effects.

Treatment Results: Descriptive Analyses

Factors Related to the Choice of an Individual Treatment

The patient factors associated with each type of treatment among 2 198 couples attending academic infertility clinics in Canada were tabulated. Of these couples, 1 325 were treated and 873 were not. Important clinical characteristics associated with treatment are presented in Table 2.4. The average duration of infertility, coital frequency, male partner's age, and income were similar. The treated group was more likely to have had a laparoscopy as part of the investigation. In addition, the female partner was slightly younger, fewer had a diagnosis of unexplained infertility, and fewer had had a previous pregnancy. Follow-up was longer, and couples were less likely to become lost to follow-up if they received treatment. This table addresses the larger issue: the treatment decision itself, a decision that is not necessarily the same as the choice of individual treatments. Thus, the data in this table are complementary to the data in Report 1, Section 3, on clinical management.

Tables 2.5(a) and 2.5(b) present the clinical characteristics among couples receiving no treatment and some of the important treatments. Tables 2.6(a) and 2.6(b) replicate Tables 2.5(a) and (b), but present the data

by number of treatments undergone. These tables give the descriptive data on which the logistic regression (Table 2.7) and the proportional hazards analyses of subsequent treatments (Tables 2.8 and 2.9) are based. A live birth outcome rather than pregnancy was chosen as the dependent variable, since this is the primary goal of the infertile couple. There were 687 live births among the 2 198 couples, 270 in the untreated group and 417 among couples who received treatment. Of the 417 live births among treated couples, 342 were attributable to the treatment given and 75 were the result of pregnancies occurring after treatment was stopped. The decision was made to discount the 75 live births that were the result of pregnancies occurring after treatment stopped; there is, therefore, a conservative bias in our analyses of the effect of treatment on the live birth rate.

The proportional hazards analysis of predictors of treatment, presented in Report 1, Section 3, Table 1.20(c), was stratified by pregnancy (yes/no); it showed that the determinants of treatment were younger female age, lack of previous treatment of the female partner, and a diagnosis of ovulation defect, endometriosis, or male defect. The variable representing social class (family income) did not influence the treatment decision. For the proportional hazards analyses of individual treatments, we ran the analyses first excluding the income variables (2 198 cases), then with income included for the 1 761 cases that had occupation information and therefore income data. Then the analyses were repeated for 2 198 couples including the income variable and with missing income data replaced with the mean income (\$43 300). In each case, the income-related hazard was similar (1.06-1.07) and its significance level was marginal (0.07-0.03). We therefore present the data from all couples with income included and the mean substituted in missing cases, because the data are consistent with those presented in Report 1, Section 3, Table 1.20(c), and Report 1, Section 4, Table 1.23.

It would be very complicated and time-consuming to evaluate the effect of particular treatments among diagnostic groups. That will be a future task for clinical researchers making use of this data base, in preparation for clinical publications. Our intention here was to evaluate among all couples, first, the effect of important treatments, and, second, the effect of subsequent treatment decisions, compared with no treatment. In each case, we also adjusted for infertility diagnosis and other patient characteristics.

Evaluating the Effect of Treatments Using Logistic Regression

Logistic regression was used to assess the contribution of the first, second, third, and fourth treatments in achieving a live birth. The method involved evaluating the first treatment compared to no treatment; a second treatment after an unsuccessful first attempt compared to no treatment; a third treatment after unsuccessful first and second attempts compared to no treatment; and a fourth treatment after unsuccessful first, second, and

third attempts compared to no treatment. The problem here and in the proportional hazards analysis is to evaluate the effectiveness of each subsequent treatment and attribute the occurrence of a pregnancy and live birth to the treatment being given. This was addressed by considering the observations terminated when the treatment under consideration was completed. One approach was to determine that any pregnancy occurring after the treatment stopped was not counted as a pregnancy. A second approach counted the pregnancy, but the treatment was considered not to have occurred (because it had been discontinued before the pregnancy). In this case, pregnancies with subsequent other treatments were always discounted. Analyses conducted using both methods showed no appreciable difference in results. Results presented here are based on the first method, mainly because it is consistent with clinical procedures.

To determine which patient characteristics were to be included, univariate analyses and multivariate stepwise logistic regression were used to identify variables that were significant in predicting pregnancy and live birth. Patient characteristics identified as significant in the analysis of important treatments were duration of infertility (DURATION), age of the female partner (FEMAGE), pregnancy history (PREGHIST), and adequacy of coitus (LT2PERWK), as well as the diagnosis of an ovulation defect, tubal defect, seminal defect, or endometriosis. In the analysis of predictors of a live birth (presented in Report 1, Section 4, Table 1.23), family income (INCOME) was associated with marginal significance and should therefore be entered as a covariate in the evaluation of treatment.

According to the logistic regression analysis, patients who had a first treatment were half (0.5395) as likely to have a live birth as those who were not treated. Longer duration of infertility, older female age, and presence of tubal defect were associated consistently with a lesser likelihood of pregnancy. Patients who had a second treatment were 40 percent as likely to have a live birth as those who were not treated. In this analysis, duration of infertility, female partner's age, secondary infertility, and the diagnosis of tubal and male defects were the other important factors. Any third or fourth treatments were also associated with lower chances of live births. Family income did not reach significance in any of these analyses.

Logistic regression, however, does not take into account the time factor before treatment starts. It ignores the fact that some patients waiting for treatment will conceive prior to starting treatment and that only those who fail to get pregnant before treatment starts will commence treatment. Thus, it would be expected that the treatment effects estimated by such an analysis might be negative, as patients who conceive easily in the observation period would not get treatment. Nor does logistic regression take into account the duration of treatment and time it takes to become pregnant. The proportional hazards model does take these factors into account, however. Coupled with the fact that some treatments are meant to be short in duration with fairly immediate effects, while others are meant to be longer term with delayed effects, this could easily account for the marked

differences in the results using logistic regression compared with those achieved using proportional hazards analysis.

Evaluating the Effect of Important Treatments Using the Cox Proportional Hazards Model

The treatments that were used most frequently as the initial therapy after registration were included in the analysis as time-dependent variables to take into account time to treatment and duration of treatment as well as time to pregnancy. Among treated couples, only live births from conceptions during the treatment were considered, as in the previous logistic regression. As in other analyses, the patient characteristics associated with a pregnancy and live birth outcome were entered as well. Some treatment categories were combined to reduce the number of treatment variables. Combination treatments listed in Table 2.1 were categorized as follows: TDI with clomiphene — TDI category; surgery with other treatments — surgery category; and IUI with clomiphene — clomiphene category. Total family income (with mean income substituted for missing data) was included among the patient characteristics in the analyses. The treatments and their odds ratios (compared to no treatment) are presented in Table 2.8, and the major treatments are summarized in Figure 1.

Some caution is necessary in interpreting and comparing the relative likelihoods calculated in this analysis. First, they are not the product of an experimental design; although known biases may be accounted for in the analyses, unknown biases may affect the results. Second, a treatment that results in pregnancy after 20 cycles will have a lower odds ratio than a treatment that results in a pregnancy after only 3 cycles of treatment. Although both treatments are effective in achieving the desired outcome, the one requiring longer treatment will appear (and in truth may be) less successful. In this way, the analysis compares the effectiveness of different intensities of response to individual treatments rather than their relative success.

Given that interpretation, and with the understanding that these results are to be considered more as guidelines for further effectiveness trials than as answers to effectiveness questions, we now discuss the various treatment observations from a clinical viewpoint.

Clomiphene, as prescribed in this study, does not appear to be effective ($p = 0.22$). In contrast, clomiphene has been evaluated in three trials among couples with unexplained infertility and seems to have an overall efficacy of approximately two times the fertility in untreated couples (Deaton et al. 1990; Fisch et al. 1989; Glazener et al. 1990). Clomiphene also seems to be effective in uncomplicated cases of ovulation deficiency, although that evidence is based on relatively low quality designs. The apparent contradiction with our results may arise because in our sample only 318 of the 642 clomiphene cases involved ovulation deficiency. Thus, the use of clomiphene in the presence of other fertility disorders lowers the

fertility that otherwise might be expected with clomiphene. Given its mode of action, clomiphene efficacy should be evaluated in short-term trials. Even among women with hypothalamic amenorrhoea, placebo-controlled trials of three months' duration would not be unethical.

Surgical treatment in this observational study was defined as laparotomy and the intraoperative procedures that were deemed necessary by the surgeon. Given that bilateral tubal obstruction was initially present in 214 couples, it would be expected that surgical treatment would be effective (relative likelihood = 2.81, $p < 0.0005$, 95% confidence interval [CI] = 1.84-4.22). The untreated live birth rate among such couples was only 5 percent. Nevertheless, surgery does not appear to be curative: the overall live birth rate for tubal obstruction was only 17 percent. Moreover, the presence of tubal defects or endometriosis (the two conditions most likely to indicate surgery) decreases the likelihood of a live birth significantly (in the analysis to 47% and 55% respectively), thus implying associated fertility defects that are not easily corrected by surgery. Post-operative adhesions are often blamed for the incomplete response to surgery, but such adhesions are also found in fertile women (Mahmood and Templeton 1990). More likely is the possibility that tubal infection is a pan-tubal disorder affecting the tubal endothelium and its function as well as causing the structural changes that indicate surgery. In some cases the tubal endothelium retains or regains its function, while in others it does not.

IUI is currently used widely as an empirical treatment for infertility. Although logical as a treatment for male infertility, its efficacy for male infertility, unexplained infertility, or cervical disorders remains unproven. The treatment does have relatively low dollar costs, time costs, and side-effects. It is used frequently in conjunction with superovulation in response to persistent infertility, also with as yet unproven efficacy. Our study results are consistent with the current literature: the relative likelihood of 1.87 ($p = 0.14$, 95% CI = 0.87-4.03) indicates that IUI is promising but unproven by conventional statistical standards.

The problem of evaluating IVF effectiveness in a way that is comparable with other treatments has been outlined. The first IVF treatment cycle appears to be the most effective infertility therapy evaluated in our study (relative likelihood = 4.48, $p = 0.0010$, 95% CI = 2.12-9.38). It is also associated with low live birth rates: 6.4 percent among 140 couples having IVF as their first treatment (Table 2.5(a)). This seeming paradox is clarified in part by other information from Table 2.5(a); the average patient having IVF had had 67 months without conception and had waited a further 14 months for IVF treatment. After 81 months of infertility, the duration of infertility alone would predict a monthly fecundity of less than 1 percent or a lifetime pregnancy expectation of about 5 percent. Thus, where expected fertility falls below IVF pregnancy rates, IVF may be an effective therapy. Nevertheless, trials are needed to demonstrate the value of IVF and related procedures in a wide range of infertile conditions.

Therapeutic donor insemination was a very effective treatment in our sample (relative likelihood = 3.42, $p = 0.0002$, 95% CI = 1.93-5.99). This treatment is used only in relation to the primary indications, which are azoospermia or prolonged infertility with severe oligospermia (fewer than five million sperm per millilitre). The live birth rate without treatment is virtually zero with azoospermia and less than 10 percent with severe oligospermia. Thus, the 38 percent live birth rate with TDI is clinically important (Table 2.5(a)). During our sample period, all donor programs changed from fresh sperm samples to sperm storage at -70°C in order to quarantine samples for six months so that donors could be tested for human immunodeficiency virus (HIV). The 38 percent live birth rate is therefore the result of higher rates formerly obtained with fresh samples and the lower rates generally associated with frozen samples. Although the treatments Pergonal[®], Danazol[®], and bromocriptine were used in the final model, their significance levels were above 0.05 and therefore are not discussed further.

The proportional hazards model was then used to evaluate the effectiveness of subsequent treatments. A summary of the analyses is presented in Table 2.9. When the first treatment is a time-dependent variable, the overall effect of the first treatment is to improve the likelihood of live birth by 73 percent ($p < 0.0005$). (With logistic regression, the initial treatment showed a negative effect on live birth and reduced the odds by approximately 50%.) A shorter duration of infertility, younger female age, and a previous pregnancy in the partnership also improved the chances of live birth. Higher family income was a marginally significant predictor of live birth, while a diagnosis of endometriosis or ovulation, tubal, or male defect reduced the likelihood of live birth. The results of the analysis of the second treatment show that it is associated with a twofold increase ($p = 0.0006$) in the likelihood of live birth, among the 464 couples who received a second treatment compared to the untreated group. Among the 189 couples who received a third treatment, the likelihood of live birth was not significantly higher ($p = 0.24$) than in the untreated group of couples. These results are summarized in Figure 2.

In considering these results, at least two underlying issues are important: first, expressed simply, the proportional hazards analysis of a second treatment (started after a mean of 19.7 months) compares this treatment experience with that of similar couples who have also been under observation for about 20 months, when fertility in the untreated group is fairly low. A second issue is the type of second treatment, a detailed analysis of which we have not done, mainly because there are too few cases within each specific treatment group. Nevertheless, Table 2.1 in this report shows that IVF is the single most frequent second or third treatment. Thus, IVF effectiveness is a notable component of the effect of any second or third treatment among the CITES couples.

Discussion

Taken together, the information in these reports represents the outcome for couples with infertility who have been referred to clinics in academic health science centres in Canada. These results are not necessarily generalizable, as there is no confirmation that such infertile couples are typical of all infertile couples. They do appear, however, to be typical of other Canadians in the same age range, as judged by their occupations.

How reliable is the evidence derived from the CITES findings? With respect to demographic and clinical predictors, the observations and the outcome are relatively free of bias. An unexpected source of bias, discussed below, can arise from the comparison of groups with different lengths of follow-up, but in general the baseline characteristics are well-defined and the outcome — pregnancy — is also clear. With respect to treatment effects, however, there are several sources of selection bias and other biases that may obscure the true treatment effect. At best, the results can be interpreted as the treatment effects that may be expected in the course of clinical practice in academic centres. At worst, the treatment effects observed, even after an analysis adjusted for known biases, may be simply the product of unknown bias. In many cases, however, these results represent the best quality of evidence available: a cohort study with prolonged follow-up in which the control group was not treated. As such, these results have two important applications: as guides for the design of randomized studies to evaluate infertility treatments, and as guides to therapy choices where superior evidence does not exist.

Baseline Data for the Design of Infertility Trials

The effect of any treatment therapy must be superior to the untreated prognosis, given similar conditions. Thus, as a preliminary step in the justification of sample sizes, one would estimate the expected prognosis among untreated couples. Because few infertile couples for whom treatment might be indicated will accept randomization if it could entail prolonged placebo therapy, trials of up to six months are most likely feasible. Table 2.10 gives the live birth rate expressed as a percentage for a range of untreated infertile conditions ($\text{live births} \times 100 \div \text{total months of observation}$). The columns show the approximate live birth rate per month, per six months, and per couple among all untreated couples with the condition who were enrolled in the study.

The duration of infertility is an important factor, and this is considered for couples with unexplained infertility. Among the CITES couples, the best prognosis (considering baseline patient characteristics) was associated with unexplained infertility. This prognosis was notably worse with prolonged infertility and decreased by about 25 percent of the initial value during every year of further infertility. Table 2.11 shows the approximate live birth rate per month, per six months, and per couple for couples with untreated, unexplained infertility arranged according to the duration of their infertility

at enrolment. Tables 2.10 and 2.11 represent the average untreated couple in the respective CITES category.

If one were planning a six-month study of, for example, a treatment for tubal infertility characterized by adhesions only, then the untreated live birth rate would be 4.6 percent (Table 2.10). If desired, a 95 percent confidence interval could be constructed around this estimate. If the expected treatment effect was three times the effect of no treatment and one wished to work with conventional power (80%) and alpha (5%, two-tailed), then the required sample size per group would be 153 for a study with one treatment and one control group (Table 2.12). Table 2.13 provides overall loss to follow-up data that might be required to calculate the final sample size.

Randomized studies are especially important because cohort observations often entail different follow-up periods for control and treated subjects. Different lengths of follow-up introduce an unexpected bias that is related to better fecundity in the earlier months of observation. When the follow-up of a group of infertile couples is analyzed, those who are more likely to get pregnant will conceive early in the observation period. Unless new couples are added, the remainder will have fewer pregnancies during the later months of observation. Thus, selecting couples according to their length of follow-up can affect the observed fecundity and the cumulative pregnancy rate.

The cumulative pregnancy rate for live births among 340 untreated couples with unexplained infertility illustrates this point. Other details on these couples, some of whom were followed for 48 months, have been reported (Collins and Rowe 1989). Fecundity was higher during the first six months compared with later months (Figure 3). When the original 340 patients were divided into two groups (67 followed for three months or less and 273 followed for more than three months), the apparent fecundity in the group with shorter follow-up was very high and the resulting cumulative pregnancy rate was much higher. Thus, bias exists even when the baseline characteristics of groups are comparable. Clearly, then, the evidence needed to demonstrate the effectiveness of infertility treatments will have to come from randomized clinical trials. If a treatment is thought to be superior, it could be tested in a group, half of whom receive two cycles of the treatment while the other half wait without treatment for two months. Such a design avoids the pitfall of randomization by cycle and does not unduly delay the desired treatment for those serving as controls.

Clinical Decision Making

The CITES data can be useful for clinical decision making in cases where superior quality information is not available. Couples with untreated, unexplained primary infertility are the reference category for most of the analyses in these reports. The most important prognostic factor is the duration of infertility. As a baseline prognosis, Figure 4 shows the live birth rate after total waiting time (duration of infertility plus time under

observation). The circles represent the actual observations, while the smoothed line is the adjusted logistic regression coefficient. Time under observation has been included with duration of infertility because the total waiting time is the only relevant concept in discussions with a given couple. One can then adjust for the individual couple's characteristics and arrive at a tailored prognosis; the plan is more conceptual than statistical, but the odds ratios in Table 2.14 serve as guidelines. It will be obvious immediately that this procedure is more successful in the middle section of the curve in Figure 4: secondary infertility cannot increase the prognosis at one year, nor can older age decrease it at 10 years by as much as the odds ratios suggest. Obviously, too, the prognosis with azoospermia or bilateral tubal obstruction does not require any such calculations. Nevertheless, the evidence from CITES can be used to estimate the couple's prognosis and help them make decisions on treatment. If the prognosis is less than that in an IVF program, then IVF may be indicated, unless there is another less costly and less complex therapy that could be tried. Typical IVF data published in 1991 were used for Figure 4.

Thus, the factors affecting treatment decisions include issues other than the efficacy of therapy. On the issue of efficacy, however, only treatments that have been demonstrated by means of acceptable clinical evidence in the form of randomized trials have proven superiority over no therapy, and the CITES study does not provide such evidence.

Table 2.1 Type and Frequency of Treatments in the Order Listed on the Follow-up Form

Treatment	Frequency							
	1st	2nd	3rd	4th	5th	6th	7th	8th
Clomid®	419	111	24	10	2	1		
Surgery	180	29	10	2	—	—	—	—
IUI-husband ¹	80	33	9	7	—	1	—	—
IVF/GIFT	140	134	95	47	27	13	5	1
Pergonal®	22	28	16	6	3	—	—	—
Danazol®	71	13	4	—	—	—	—	—
p4supp ²	18	13	3	—	—	—	—	—
Male treatment ³	43	9	3	—	—	—	—	—
Bromocriptine	16	6	3	—	—	—	—	—
TDI	130	29	7	5	1	—	1	—
Other	44	36	8	4	1	—	—	1

Table 2.1 (cont'd)

Treatment	Frequency							
	1st	2nd	3rd	4th	5th	6th	7th	8th
Clomid® & IUI	32	5	—	—	—	—	—	—
Clomid® & TDI	20	1	3	—	—	—	—	—
Clomid® & other	72	10	3	—	—	—	—	—
Surgery/Clomid®	24	3	—	—	—	—	—	—
Surgery/Danazol®	8	2	—	1	—	—	—	—
Surgery/other	6	2	1	—	—	—	—	—
Total	1 325	464	189	82	34	15	6	2

¹ Intra-uterine insemination using male partner's sperm.

² Progesterone suppositories.

³ Male treatments, usually varicocoelectomy or Clomid®.

Table 2.2 Type and Frequency of Treatments in "Other" Category

Treatment	Frequency
Estradiol	14
Conjugated estrogens	11
Megace®	9
Dexamethasone	21
Provera®	32
Tamoxiphen	11
Norinyl®	2
Efamol®	2
Human chorionic gonadotropin (hCG) injections	20
Immunotherapy	1
Non-Steroidal Anti-Inflammatory Drug (NSAID)	1
Premarin® + Provera®	2

Table 2.2 (*cont'd*)

Treatment	Frequency
Dexamethasone + Provera [®]	2
Ovral [®]	2
Dexamethasone + tamoxiphen	2
hCG + tamoxiphen	2
Estradiol + Megace [®]	1
Total	135

Table 2.3 Comparison of (i) the Average Interval in Months from Registration to the Start of a Specific Treatment and (ii) the Average Time on Treatments Specific to an Infertility Disorder and Those Prescribed in the Absence of the Related Infertility Disorder (Augmentation Therapy)

Treatment	All couples	Specific treatment	Augmentation treatment
Clomiphene			
no.	642	318	324
months to start treatment: mean (S.D.)	7.3 (9.7)	4.6 (6.5)	10.1 (11.5)
months on treatment: mean (S.D.)	6.6 (6.0)	6.8 (6.1)	6.4 (6.0)
Surgery			
no.	260	229	31
months to start treatment: mean (S.D.)	9.2 (9.8)	8.1 (7.2)	17.6 (18.6)
IUI			
no.	157	89	68
months to start treatment: mean (S.D.)	10.2 (11.5)	7.6 (9.7)	13.5 (12.7)
months on treatment: mean (S.D.)	5.6 (5.6)	6.3 (6.2)	4.7 (4.8)
IVF			
no.	239	116	123
months to start treatment: mean (S.D.)	22.0 (17.5)	18.2 (16.4)	25.6 (17.8)
number of IVF cycles: mean (S.D.)	1.9 (1.1)	2.0 (1.1)	1.9 (1.1)

Table 2.3 (cont'd)

Treatment	All couples	Specific treatment	Augmentation treatment
Pergonal®			
no.	81	44	37
months to start treatment: mean (S.D.)	15.0 (13.3)	10.4 (9.4)	20.4 (15.3)
months on treatment: mean (S.D.)	4.1 (4.4)	3.5 (3.4)	4.7 (5.3)
Bromocriptine			
no.	38	8	30
months to start treatment: mean (S.D.)	6.5 (6.1)	4.9 (4.2)	6.9 (6.5)
months on treatment: mean (S.D.)	6.4 (5.6)	5.7 (6.0)	6.6 (5.5)
TDI			
no.	177	171	6
months to start treatment: mean (S.D.)	9.0 (11.5)	8.1 (9.7)	35.4 (24.1)
months on treatment: mean (S.D.)	5.2 (5.0)	5.3 (5.0)	3.2 (3.4)
Danazol®			
no.	98	89	9
months to start treatment: mean (S.D.)	8.0 (9.8)	6.8 (8.4)	20.4 (14.2)
months on treatment: mean (S.D.)	5.1 (2.9)	5.1 (2.9)	5.2 (1.8)

Table 2.4 Comparison of Clinical Characteristics Between Treated and Untreated Couples Attending Academic Infertility Clinics in Canada

Clinical characteristics	Treated (n = 1 325)	Untreated (n = 873)	Significance level
Duration of infertility (months)	42.0	41.0	0.3
Female partner's age (years)	29.4	29.8	0.02
Male partner's age (years)	32.8	32.1	0.14
Total family income (\$000)	43.0	43.7	0.4
Observed time (months)	29.2	21.0	< 0.00005
Lost to follow-up (%)	8.7	20.2	< 0.00005
Secondary infertility (%)	20.5	25.4	0.007
Coital frequency less than twice per week (%)	15.9	17.3	0.43
Unexplained infertility (%)	16.0	40.1	< 0.00005
Laparoscopy completed (%)	67.9	55.0	< 0.00005

Table 2.5(a) Clinical Characteristics and Timing of the First Treatment Decision Among Couples Attending Academic Infertility Clinics in Canada

First treatment	Valid number	Duration of infertility (mean months)	Female age (mean years)	Secondary infertility (%)	Infrequent coitus ⁴ (%)	Income (mean \$000)	Time to start on first treatment (mean months)	Live births per couple ⁵ (%)
Untreated	873	41	29.8	25.4	17.3	43.7	—	30.9
Clomiphene ¹	523	38	29.2	23.1	18.4	42.9	6.1	19.3
Surgery ²	218	40	29.2	20.2	11.0	41.9	7.6	16.5
IUI	80	44	29.8	17.5	25.0	41.7	7.1	18.8
IVF/GIFT	140	67	31.6	20.0	18.6	45.8	14.4	6.4
TDI ³	150	43	28.1	10.0	9.3	43.4	6.4	38.0
All other	214	39	29.1	22.9	14.5	43.6	6.3	14.0
Total	2 198							
Overall mean		42	29.5			43.3	7.4	
Overall percentage				22.4	16.5			31.3

¹ Clomiphene includes Clomid® and IUI or Clomid® and “other” treatment when used in combination.

² Surgery includes treatments immediately following surgery.

³ TDI includes TDI and Clomid® when used in combination.

⁴ Coitus less often than twice per week.

⁵ Pregnancies occurring after the specific treatment stopped are not counted in the live birth rate for that treatment.

Table 2.5(b) Clinical Diagnoses and the First Treatment Decision Among Couples Attending Academic Infertility Clinics in Canada

First treatment	Valid number	Unexplained infertility (%)	Ovulation defect (%)	Tubal defect (%)	Endometriosis (%)	Male defect (%)
Untreated	873	40.1	14.3	22.7	7.8	24.3
Clomiphene	523	23.7	56.6	13.2	10.9	16.6
Surgery	218	1.8	12.4	82.6	24.3	13.8
IUI	80	20.0	11.3	10.0	10.0	68.8
IVF/GIFT	140	25.7	7.1	55.7	17.1	10.0
TDI	150	0.7	4.0	3.3	5.3	98.7
All other	214	14.5	18.2	18.7	43.9	27.1
Total	2 198					
Overall percentage ¹		19.3	23.3	26.3	14.2	27.5

¹ This table includes *all* diagnoses; the rows do not necessarily add to 100%.

Table 2.6(a) Clinical Characteristics and Timing of the First Four Treatments Among Couples Attending Academic Infertility Clinics in Canada

Treatment number	Valid number	Duration of infertility (mean months)	Female age (mean years)	Secondary infertility (%)	Infrequent coitus ¹ (%)	Income (mean \$000)	Time to start of treatment (mean months)	Live births per couple (%)
0	873	41	29.8	25.4	17.3	43.7	—	30.9
1	1 325	42	29.4	20.5	15.9	43.0	7.4	18.7
2	464	46	29.7	17.9	15.9	44.0	19.7	13.8
3	189	47	30.0	19.6	16.4	43.2	27.0	8.5
4	82	50	30.2	14.6	14.6	44.4	34.3	11.0

¹ Coitus less often than twice per week.

Table 2.6(b) Clinical Diagnoses and the First Four Treatments Among Couples Attending Canadian Health Science Centre Infertility Clinics

Treatment number	Valid number	Unexplained infertility (%)	Ovulation defect (%)	Tubal defect (%)	Endometriosis (%)	Male defect (%)
0	873	40.1	14.3	22.7	7.8	24.3
1	1 325	16.0	29.2	28.7	18.4	29.6
2	464	17.9	26.7	30.6	22.8	27.2
3	189	15.9	24.9	36.5	21.7	27.0
4	82	18.3	22.0	35.4	22.0	26.8

Note: This table includes *all* diagnoses; the rows do not necessarily add to 100%.

Table 2.7 The Relative Probability of Live Birth After a First, Second, Third, or Fourth Treatment, Adjusting for Differences in Patient's Clinical Characteristics: Results of a Logistic Regression Analysis

Variable	First treatment		Second treatment		Third treatment		Fourth treatment	
	Odds ratio	Signifi- cance	Odds ratio	Signifi- cance	Odds ratio	Signifi- cance	Odds ratio	Signifi- cance
DURATION	0.9842	0.0000	0.9831	0.0000	0.9792	0.0000	0.9781	0.0000
FEMAGE	0.9618	0.0026	0.9504	0.0025	0.9571	0.0143	0.9601	0.0249
PREGHIST	**	**	0.7071	0.0256	**	**	**	**
LT2PERWK	**	**	**	**	**	**	**	**
Ovulation defect	**	**	**	**	**	**	**	**
Tubal defect	0.5130	0.0000	0.5449	0.0004	0.3373	0.0011	0.5127	0.0007
Endometriosis	0.6176	0.0055	**	**	**	**	**	**
Male defect	**	**	0.5930	0.0013	0.5186	0.0003	0.5401	0.0008
*INCOME	**	**	**	**	**	**	**	**
First treatment	0.5395	0.0000						
Second treatment			0.3927	0.0000				
Third treatment					0.2314	0.0000		
Fourth treatment							0.3288	0.0026
Number of cases	2 198		1 337		1 062		955	
Number treated	1 325		464		189		82	

* occupational variable; ** odds ratio for this term was not significantly different from 1

Notes: In cases with missing family income data, the mean for family income was substituted. Since time to pregnancy and time to start of treatment are not adjusted for in logistic regression, the evidence presented is of less value than that obtained by using proportional hazards analysis (Table 2.9), where quite different results were obtained with respect to the relationship between the use of treatment and a live birth outcome.

Table 2.8 The Relative Probability of Live Birth Associated with the First Type of Treatment Used: A Stepwise Proportional Hazards Analysis

Final model:

Variable	Relative hazard	Significance level
DURATION	0.9846	< 0.0005
Tubal defect	0.4671	< 0.0005
Endometriosis	0.5481	0.0005
PREGHIST	1.4781	0.0010
*INCOME	1.0629	0.0927
FEMAGE	0.9660	0.0108
Male defect	0.5286	< 0.0005
Surgery	2.8073	< 0.0005
IVF	4.4791	0.0010
Pergonal [®]	3.2630	0.0899
Danazol [®]	1.8756	0.0955
bromocriptine	3.0261	0.0646
TDI	3.4153	0.0002

Variables not in the final model and the significance levels necessary for their entry:

Variable	Significance Level to Enter
LT2PERWK	0.4649
Ovulation defect	0.1597
IUI ¹	0.1369
p4supp ²	0.3734
male treatment	0.5023
other treatment ³	0.9243
Clomid [®]	0.2181

* occupational variable

¹ intrauterine insemination using male partner's sperm.

² progesterone suppositories.

³ "Other" treatment category.

Note: In this analysis, in cases with missing family income data, the mean family income was substituted.

Table 2.9 The Relative Probability of Live Birth Associated with Any First, Second, or Third Treatment: A Stepwise Proportional Hazards Analysis

Variable	First treatment		Second treatment		Third treatment	
	Relative hazard	Significance level	Relative hazard	Significance level	Relative hazard	Significance level
DURATION	0.9854	< 0.0005	0.9866	< 0.0005	0.9832	< 0.0005
FEMAGE	0.9621	0.0045	0.9524	0.0011	0.9502	0.0009
PREGHIST	1.4667	0.0012	1.7430	< 0.0005	1.4951	0.0042
LT2PERWK	**	0.2703	**	0.5742	**	0.5656
Ovulation defect	0.7050	0.0093	0.7589	0.0763	**	0.5077
Tubal defect	0.5529	< 0.0005	0.5105	< 0.0005	0.4981	< 0.0005
Endometriosis	0.5626	0.0003	0.5561	0.0018	0.5991	0.0225
Male defect	0.5951	0.0002	0.5302	0.0001	0.5563	0.0011
*INCOME	1.0681	0.0681	**	0.5319	**	0.7671
Time to laparoscopy	**	0.7044	**	0.5373	**	0.5780
First treatment	1.7294	< 0.0005				
Second treatment			2.1889	0.0006		
Third treatment						0.2442
Number of cases	2 198		1 337		1 062	
Number treated	1 325		464		189	

* occupational variable
** not significant

Note: In this analysis, in cases with missing family income data, the mean family income was substituted.

Table 2.10 Live Birth Rate Among Untreated Couples¹ with Various Infertility Diagnoses

Primary clinical diagnosis	No. of couples	Months of observation	No. of live births	Live birth rate (%)		
				Per month	Per first 6 months	Per couple
Unexplained	350	21.0	125	1.7	3.8	35.7
Ovulation defect	103	18.5	45	2.4	6.2	43.7
oligomenorrhoea	100	18.1	44	2.4	6.2	44.0
amenorrhoea	3	29.1	1	—	—	33.3
Seminal defect	184	19.9	45	1.2	2.2	24.5
oligospermia	143	17.9	45	1.8	3.0	31.5
azoospermia	41	27.0	0	0.0	0.0	0.0
Tubal defect	183	24.0	36	0.8	1.6	19.7
adhesions	29	15.4	13	2.9	4.6	44.8
partial obstruction	90	22.9	20	1.0	1.9	22.2
total obstruction	64	29.4	3	0.2	0.0	4.7
Endometriosis	41	22.2	12	1.3	1.3	29.3
mild	28	21.0	11	1.9	1.9	39.3
moderate/severe	13	24.6	1	0.3	0.0	7.7
Other (uterine/cervical)	12	11.5	7	5.1	7.4	58.3
Total	873		270			
Overall mean		21.0				
Overall percentage				1.5	3.1	30.9

¹ The effect of treatment on live birth is given in Tables 2.8 and 2.9.

Table 2.11 Live Birth Rate Among Untreated Couples with Unexplained Infertility

Duration of infertility	No. of couples	Months of observation	No. of live births	Live birth rate (%)		
				Per month	Per first 6 months	Per couple
1-2 years	157	17.6	72	2.6	5.0	45.9
2-3 years	71	18.9	23	1.7	3.7	32.4
3-5 years	73	29.0	20	0.9	3.3	27.4
over 5 years	49	23.5	10	0.9	1.2	20.4
Total	350		125			
Overall mean		21.0				
Overall percentage				1.7	3.8	35.7

Table 2.12 Table of Sample Sizes (power 0.80, α 0.05)

Control (%)	Treatment effect						
	1.5	2.0	2.5	3.0	4.0	5.0	
1	2 455	2 455	819	819	451	300	
2	3 990	1 211	629	403	221	147	
3	1 585	796	350	264	144	96	
4	1 947	589	304	195	108	71	
5	1 114	464	217	153	83	55	
10	721	215	110	70	37	24	
15	399	132	65	42	21	13	
20	312	91	45	27	13		
25	214	66	31	19			

Table 2.13 Loss to Follow-up Rates at 3, 6, 12, and 24 Months After Registration

Months after registration	Couples lost to follow-up	
	Number*	Percentage
at 3 months	56	2.5
at 6 months	80	3.6
at 12 months	126	5.7
at 24 months	262	11.9
End-of-study loss to follow-up	291	13.2

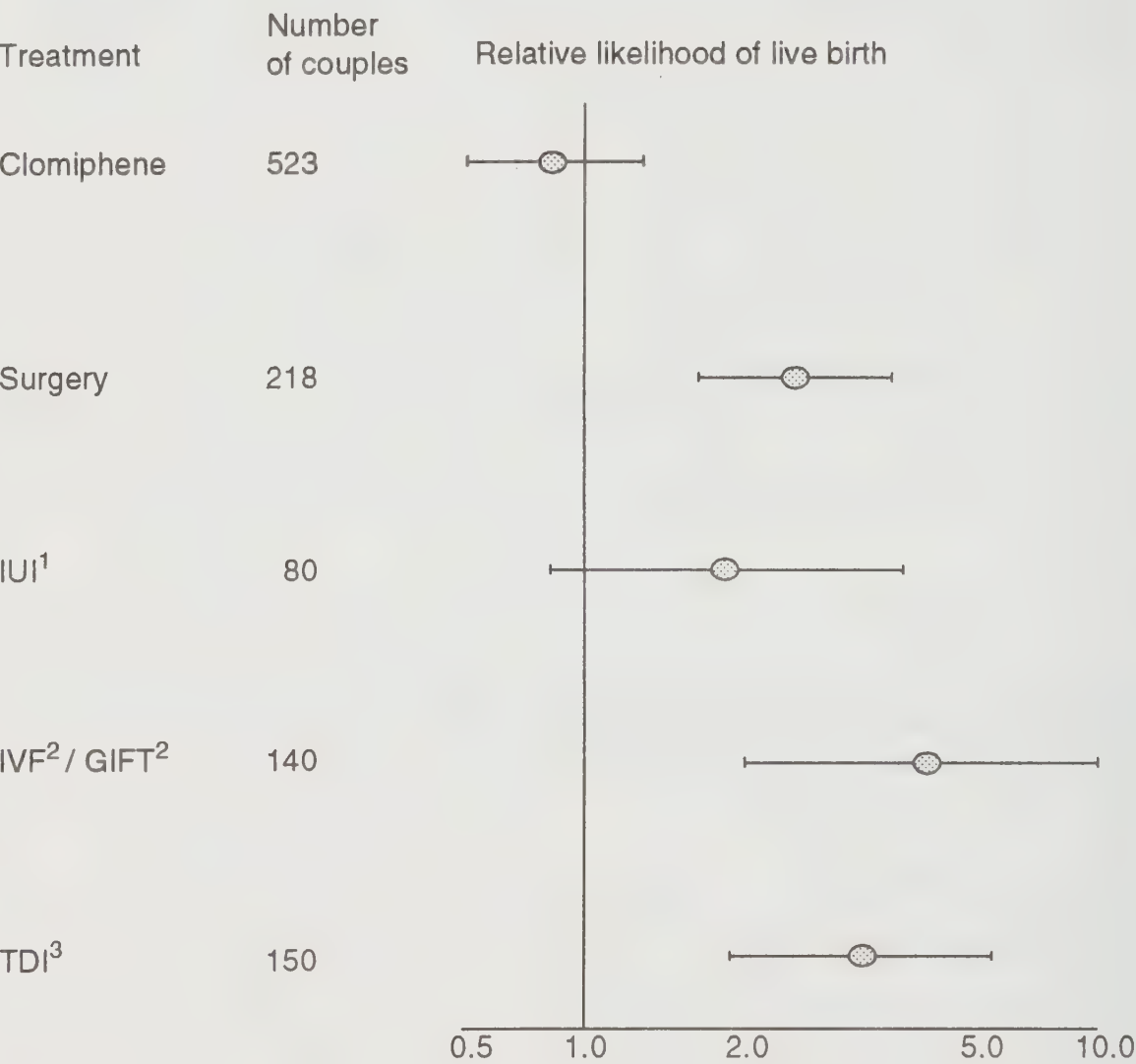
* cumulative

Table 2.14 Adjusted Relative Risk Scores and Confidence Limits for Predictors of Live Birth Among Couples Attending Academic Infertility Clinics in Canada

Predictors of live birth	Adjusted relative risk (and 95% CI)
Previous pregnancy	1.38 (1.14-1.70)
Coital frequency less than 2× per week	0.90 (0.71-1.14)
Duration of infertility ≤ 36 months	1.50 (1.24-1.82)
Female partner's age ≤ 30 years	1.33 (1.15-1.67)
Ovulation defect	0.93 (0.76-1.14)
Tubal defect	0.50 (0.39-0.62)
Endometriosis	0.64 (0.46-0.78)
Male defect	0.92 (0.74-1.14)
Family income (in \$10 000)	1.05 (0.99-1.10)

Note: The rates are adjusted for the time-dependent variables, treatment, and laparoscopy.

Figure 1. Adjusted Relative Risk Scores and Confidence Interval for the Effect of the First Treatment Decision on Live Birth Among Infertile Couples



¹ intrauterine insemination
² *in vitro* fertilization or gamete intrafallopian transfer
³ therapeutic donor insemination

Figure 2. Adjusted Relative Risk Scores and 95 Per Cent Confidence Interval for the Effect of the First, Second, and Third Treatment Decision on Live Birth Among Infertile Couples

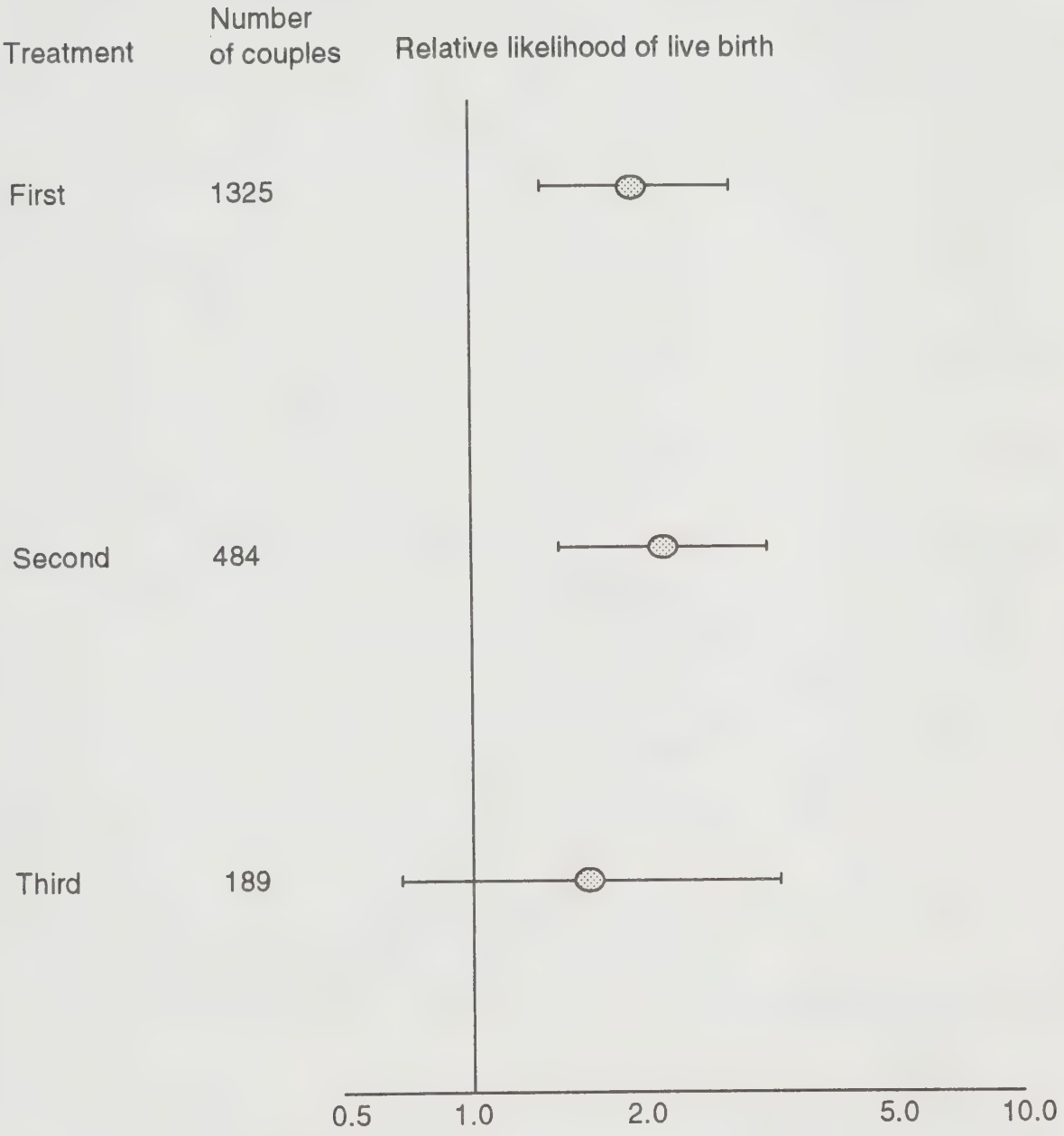
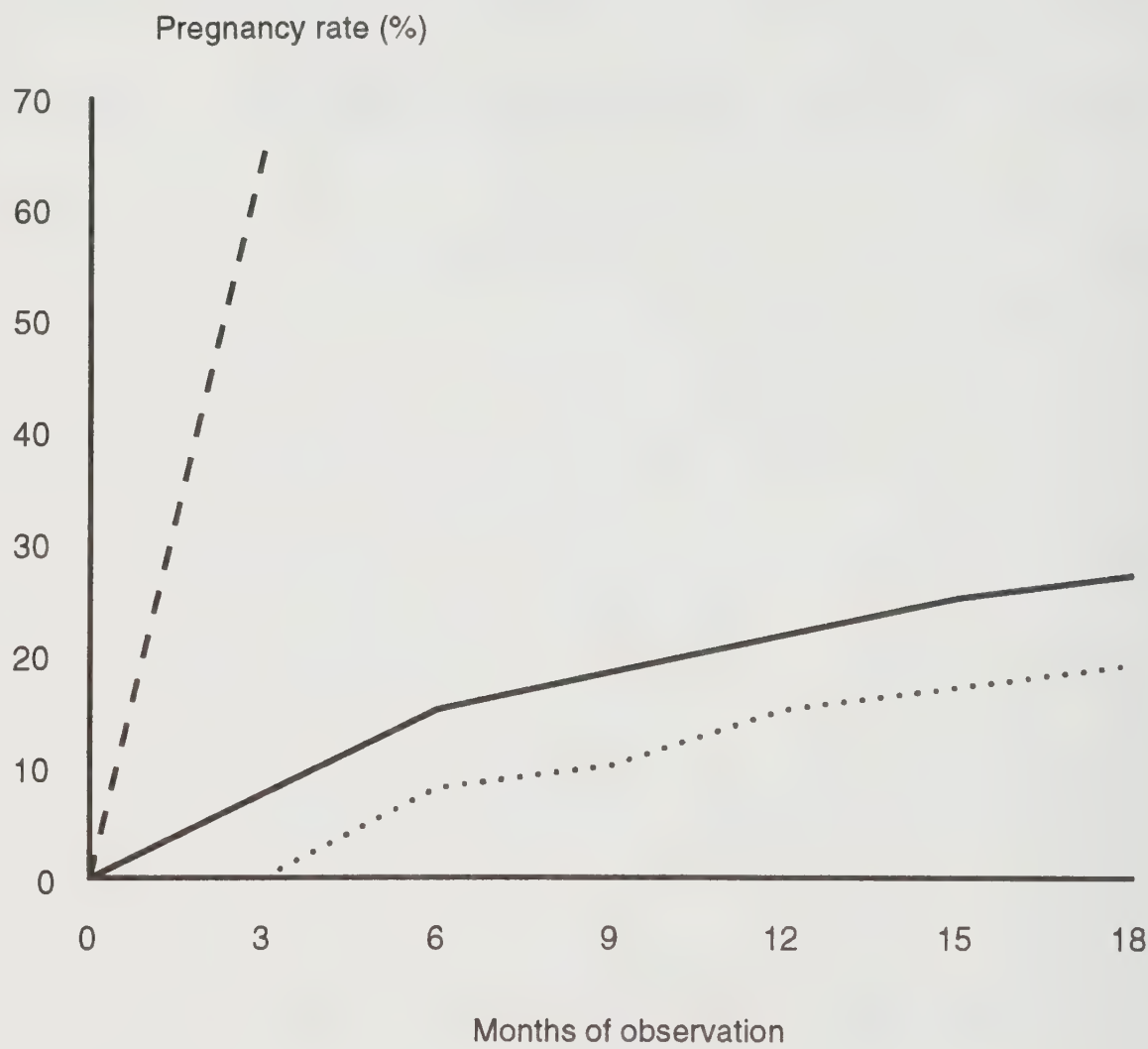
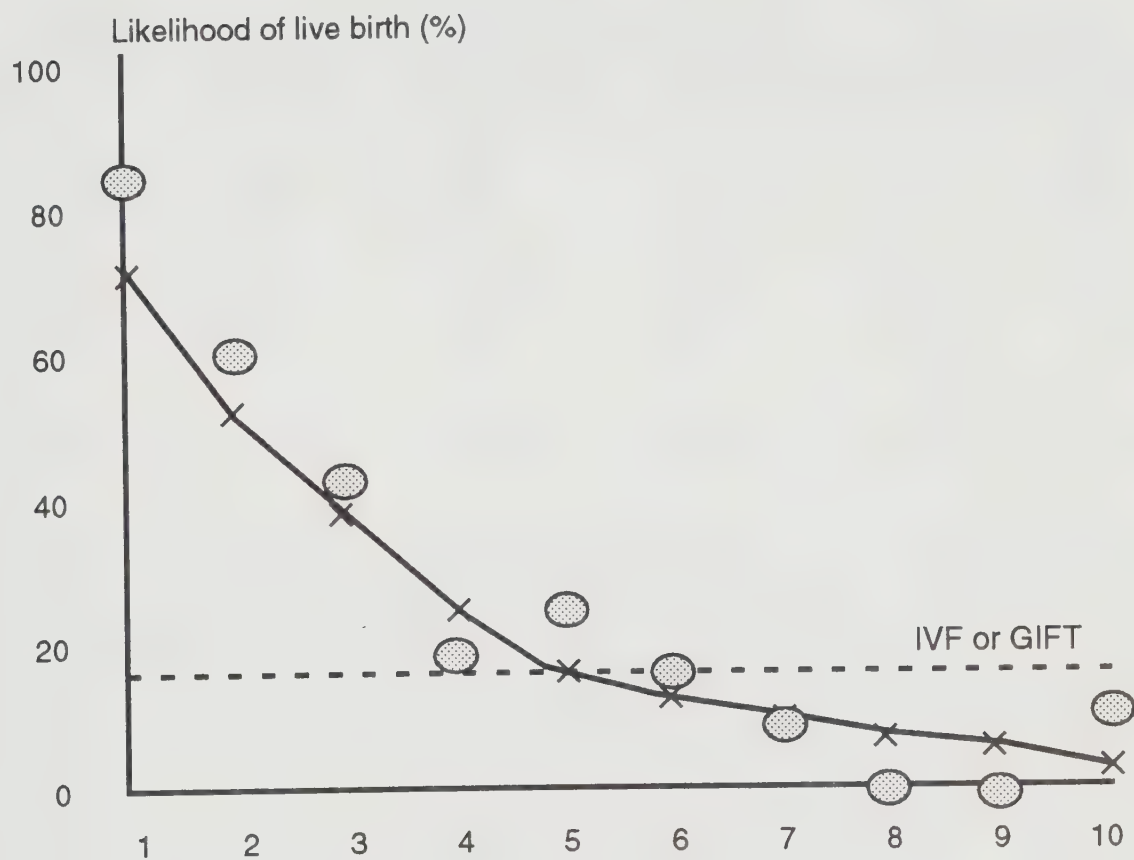


Figure 3. Cumulative Pregnancy Rates Among 340 Untreated Couples with Unexplained Infertility



- - - Cumulative pregnancy rates among 340 untreated couples with unexplained infertility
- 67 of the same couples followed 3 months or less
- The remaining 273 couples, followed more than 3 months

Figure 4. Live Birth Rate by Duration at End of Observations*



* Adjusted for female age, laparoscopy, tubal defect, and male defect

Note: Pregnancy history, coital frequency, ovulation defect, endometriosis, and income were not significant predictors in this analysis

Report 3: Updating the Follow-up Data on Infertile Couples

Five centres participated in updating the information on infertile couples enrolled in CITES: Foothills Hospital, University of Calgary; McMaster University Medical Centre; Kingston General Hospital, Queen's University; Ottawa Civic Hospital, University of Ottawa; and Grace Maternity Hospital, Dalhousie University.

All couples in the five centres who did not become pregnant during the course of the original study were to be contacted to update their treatment and outcome information. We were successful in updating the records of 833 (74%) of the couples who were to be followed, as can be seen below:

Infertility centre	Number of patients	Number not pregnant during study	Attempted to contact	Updated follow-up
Calgary	88	61	61	32
Dalhousie	473	321	321	266
Queen's	92	57	57	44
McMaster	739	573	573	457
Ottawa	185	113	52	34
Total	1 567	1 125	1 064	833

Information for all couples (updated and not) for the five centres is presented in Tables 3.1 to 3.10. Tables 3.1 and 3.2 compare the change in status, pregnancy rates, treatment rates, months of observation, etc., before and after the update. In Table 3.1, the original status was left unchanged for couples we were unable to contact. There were 192 pregnancies among couples who were not pregnant prior to updating, and some of these were among patients who had originally been lost to follow-up. In Table 3.2, treatment-independent pregnancies are pregnancies that occurred before the start of treatment or after treatment was stopped. In the other tables in this section, this distinction is not made, and treated pregnancy rates are based on pregnancies occurring in the group that received treatment and includes pregnancies that occurred even after treatment was stopped. It is only in the treatment section of this report, where the effectiveness of treatment is evaluated, that we distinguish again between pregnancies that occurred during treatment and those that are treatment-independent.

Tables 3.3 and 3.4 present the updated data arranged by centre, Tables 3.5 and 3.6 by family income, Tables 3.7 and 3.8 by female occupation, and Tables 3.9 and 3.10 by male occupation. The breakdown by individual centre can be found in Tables 1.14-1.18(b) in Report 1, Section 2.

The results presented in Reports 1 and 2 are based on the updated information.

Table 3.1 Comparison of Status Before and After Updating the Follow-up at Calgary, Dalhousie, Queen's, McMaster, and Ottawa Centres

Status	Before update		After update	
	Number	Percentage	Number	Percentage
Not pregnant	621	39.6	458	29.2
Lost to follow-up	300	19.1	158	10.1
Adopted	38	2.4	115	7.3
Disinterested	155	9.9	191	12.2
Pregnant	453	28.9	645	41.2

Table 3.2 Comparison of Pregnancy Rates, Treatment Rates, Time Under Observation in Clinic, and Time from Registration to Start of Treatment Before and After Updating Follow-up at Calgary, Dalhousie, Queen's, McMaster, and Ottawa Centres

Variable	Before update		After update	
	Number	Percentage	Number	Percentage
Number of pregnancies				
With treatment (% of treated couples)	213	26	289	31
Treatment-independent	240		356	
Before treatment (% of untreated couples)	210	29	271	42
After treatment stopped (% of treated couples)	30	4	85	7
Total pregnancies among 1 567 couples	453	29	645	41
Received treatment	831	53	926	59
Not treated	736	47	641	41
Average number of months observed	15.2		30.0	
Average number of months to start of treatment	6.6		8.4	

Table 3.3 Time Under Observation in Clinic, Time from Registration to Start of Treatment, and Loss to Follow-up Rates After Updating the Status of Infertile Couples at Calgary, Dalhousie, McMaster, Queen's, and Ottawa Centres

Infertility centre	Valid number	Observed time (months)		Time to start of treatment (months)		Loss to follow-up (%)
		Mean	S.D.	Mean	S.D.	
Calgary	92	34.7	28.8	11.5	9.0	16.3
Dalhousie	473	33.7	26.9	8.8	10.3	7.0
Queen's	88	39.1	30.9	10.6	9.6	8.0
McMaster	729	27.9	23.0	7.8	9.8	12.1
Ottawa	185	22.0	20.3	8.0	8.1	8.1
Total	1 567					
Overall mean, S.D.		30.0	25.2	8.4	9.8	
Overall percentage						10.1
F for linearity		12.6		2.2		
p value		0.000		0.07		
χ^2 4 df						13.4
p value						0.0096

Table 3.4 Treatment and Pregnancy Rates After Updating the Status of Infertile Couples at Calgary, Dalhousie, McMaster, Queen's, and Ottawa Centres

Infertility centre	Valid number	Percentage treated	Number pregnant	Total pregnancy rate (%)	Treated pregnancy rate (%)	Untreated pregnancy rate (%)
Calgary	92	43.5	39	42.4	40.0	44.2
Dalhousie	473	51.0	201	42.5	39.4	45.7
Queen's	88	45.5	38	43.2	42.5	43.8
McMaster	729	68.3	285	39.1	41.6	33.8
Ottawa	185	57.8	82	44.3	36.4	55.1
Total	1 567	59.1	645	41.2	40.4	42.3
χ^2 4 df		54.8		2.6	1.2	13.4
p value		0.0000		0.6	0.9	0.01

Table 3.5 Time Under Observation in Clinic, Time from Registration to Start of Treatment, and Loss to Follow-up Rates After Updating the Status of Infertile Couples at Calgary, Dalhousie, McMaster, Queen's, and Ottawa Centres, Arranged by Total Family Income

Total family income quartile	Valid number	Observed time (months)		Time to start of treatment (months)		Loss to follow-up (%)
		Mean	S.D.	Mean	S.D.	
Lower	261	30.2	10.8	8.1	8.9	11.5
Lower middle	274	33.0	10.9	9.6	11.3	6.9
Upper middle	294	32.6	11.1	8.6	10.0	8.5
Upper	329	29.0	10.8	7.7	8.2	8.2
Missing	409	26.7	10.4	8.0	10.0	13.9
Total	1 567	30.0	10.8	8.4	9.8	10.1
F for linearity 3 df ¹		1.6		1.2		
p value		0.2		0.3		
χ^2 3 df						3.7
p value						0.29

¹ Significance tests were performed using non-missing data.

Table 3.6 Treatment and Pregnancy Rates After Updating the Status of Infertile Couples at Calgary, Dalhousie, McMaster, Queen's, and Ottawa Centres, Arranged by Total Family Income

Total family income quartile	Valid number	Percentage treated	Number pregnant	Total pregnancy rate (%)	Treated pregnancy rate (%)	Untreated pregnancy rate (%)
Lower	261	57.5	107	41.0	36.9	47.7
Lower middle	274	62.0	113	41.2	38.8	45.2
Upper middle	294	56.1	130	44.2	46.1	41.9
Upper	329	52.6	151	45.9	42.2	50.0
Missing	409	65.5	144	35.2	39.2	27.7
Total	1 567	59.1	645	41.2	40.4	42.3
χ^2 3 df ¹		5.6		2.0	3.7	2.0
p value		0.1		0.6	0.3	0.6

¹ Significance test was performed using non-missing data.

Table 3.7 Time Under Observation in Clinic, Time from Registration to Start of Treatment, and Loss to Follow-up Rates After Updating the Status of Infertile Couples at Calgary, Dalhousie, McMaster, Queen's, and Ottawa Centres, Arranged by Female Occupation

Female occupation	Valid number	Observed time (months)		Time to start of treatment (months)		Loss to follow-up (%)
		Mean	S.D.	Mean	S.D.	
Professional	419	29.4	11.2	7.5	9.0	7.9
Services	419	30.8	11.3	8.6	9.8	7.4
Industry	102	32.6	10.4	9.3	10.8	5.9
Unemployed	211	29.4	10.7	8.5	9.6	14.7
Missing	416	29.4	10.2	8.6	10.2	13.7
Total	1 567	30.0	10.8	8.4	9.8	10.1
F for linearity 3 df ¹		0.6		0.8		
p value		0.6		0.5		
χ^2 3 df						11.7
p value						0.008

¹ Significance tests were performed using non-missing data.

Table 3.8 Treatment and Pregnancy Rates After Updating the Status of Infertile Couples at Calgary, Dalhousie, McMaster, Queen's, and Ottawa Centres, Arranged by Female Occupation

Female occupation	Valid number	Percentage treated	Number pregnant	Total pregnancy rate (%)	Treated pregnancy rate (%)	Untreated pregnancy rate (%)
Professional	419	55.1	187	44.7	45.9	43.1
Services	419	58.7	177	42.2	39.0	46.8
Industry	102	56.9	36	35.3	29.3	43.2
Unemployed	211	53.1	82	38.9	32.1	46.5
Missing	416	67.1	163	39.2	42.7	32.1
Total	1 567	59.1	645	41.2	40.4	42.3
χ^2 3 df ¹		2.1		3.0	9.0	0.65
p value		0.5		0.3	0.03	0.9

¹ Significance test was performed using non-missing data.

Table 3.9 Time Under Observation in Clinic, Time from Registration to Start of Treatment, and Loss to Follow-up Rates After Updating the Status of Infertile Couples at Calgary, Dalhousie, McMaster, Queen's, and Ottawa Centres, Arranged by Male Occupation

Male occupation	Valid number	Observation time (months)		Time to start of treatment (months)		Loss to follow-up (%)
		Mean	S.D.	Mean	S.D.	
Professional	407	28.5	10.9	7.3	7.5	6.9
Services	228	31.1	11.8	10.3	12.5	10.1
Industry	537	31.2	10.8	8.2	9.6	8.2
Unemployed	12	23.9	11.1	3.9	4.0	8.3
Missing	383	29.3	10.0	8.7	10.3	16.2
Total	1 567	30.0	10.8	8.4	9.8	10.1
F for linearity 3 df ¹			1.170		3.1	
p value			0.3		0.0026	
χ^2 3 df						2.0
p value						0.6

¹ Significance tests were performed using non-missing data.

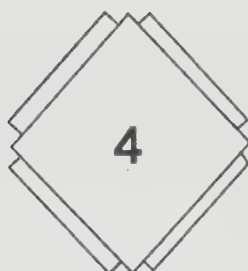
Table 3.10 Treatment and Pregnancy Rates After Updating the Status of Infertile Couples at Calgary, Dalhousie, McMaster, Queen's, and Ottawa Centres, Arranged by Male Occupation

Male occupation	Valid number	Percentage treated	Number pregnant	Total pregnancy rate (%)	Treated pregnancy rate (%)	Untreated pregnancy rate (%)
Professional	407	55.0	195	47.9	41.5	55.7
Services	228	51.3	89	39.0	39.3	38.7
Industry	537	60.5	218	40.6	40.0	41.5
Unemployed	12	66.7	4	33.3	25.0	50.0
Missing	383	65.8	139	36.3	40.9	27.5
Total	1 567	59.1	645	41.2	40.4	42.3
χ^2 3 df ¹		6.8		7.2	1.0	11.1
p value		0.08		0.07	0.8	0.01

¹ Significance test was performed using non-missing data.

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Implementing Shared Patient Decision Making: A Review of the Literature

Raisa B. Deber, Hélène Bouchard, and Ann Pendleton



Executive Summary

This literature review examines issues surrounding patient preferences in the area of reproductive health care. Part I contains a statement and summary of the underlying premises. Part II asks to what extent individuals *wish* to participate in decision making about their own care. The ethical justification for patient involvement is described, and the literature on patient preferences for participation in decision making is reviewed. It suggests that patients wish to be better informed, but do not want to participate in making treatment decisions. However, it may be argued that such research fails to distinguish between two elements of choice, that is, *problem solving* and *decision making*. Problem solving refers to the search for the single correct solution and, thus, requires expertise (e.g., medical diagnosis). In contrast, decision making refers to choosing a course of action, which often will require making trade-offs among various alternatives, and considering values and preferences. This review examines the role patients might wish to play in light of this distinction, concluding that greater information should be presented to patients to facilitate patient empowerment. New reproductive technologies (NRTs) illustrate the clinical situation most suited to the participatory ideal. Potential users are sufficiently healthy to comprehend the relevant information and make decisions. The decisions are elective, choices are available, and

users have time to weigh options. Most important decisions about reproduction involve personal moral values or lifestyle preferences about which patients are more knowledgeable than their clinicians.

Part III examines how a "good" outcome is measured. It describes decision analysis and utility theory, and examines what outcomes appear to be important when considering new reproductive technology. The approach of classic utility theory often assigns little value to health states that are undesirable but not so horrible that one would rather be dead, and leads to such unappealing conclusions as "risk-averse individuals must find chemotherapy less unpleasant than they say they do, since they are unwilling to accept much risk of death to escape its side-effects."

A utility index based on classical utility theory appears to be comparatively insensitive to differences in quality of life and comparatively sensitive to differences in life expectancy. Accordingly, the existing risk-based methods of measuring patient values tend to understate the impact of interventions that improve quality of life, and confound the individual's view of health with other factors. Policy implications of this bias limit policy makers' ability to use cost-utility approaches in allocating resources and are particularly important in analyzing NRTs. Use of the decision-rule approach could permit disentanglement of the value placed on an outcome from the level of risk acceptable to obtain that outcome, and thus permit wider use of health-status measurement approaches.

Part IV examines the policy context and considers whose values and wishes should determine policy. It proposes a typology of NRTs and suggests that the extent to which either individuals or society should have power of decision will vary accordingly.

Because grouping all NRTs under one umbrella term leaves unclear the extent to which individual preferences should dictate policy, this paper attempts to categorize NRTs. One category of NRTs — which includes microsurgery — resembles standard medical treatments, which do not challenge beliefs as to appropriate family structure. Technology assessment, cost-effectiveness analysis, and decision analysis provide tools for studying this category of procedures. Issues surrounding payment and access to NRTs will arise, as with other forms of therapy. The analysis is more complex than for other medical treatments only because risk and benefit must be evaluated for both mother and potential offspring.

In addition to the risk- and cost-benefit questions, the second category of NRTs — which includes *in vitro* fertilization (IVF) and donor insemination (DI) by partner — adds the question of separating reproduction from sex. There may be a psychic impact of this separation that is of great concern to some and little concern to others; however, there is little threat to conceptions of family structure. In general, most societies tolerate this category of NRTs, considering it a concern that individuals should decide for themselves. Issues surrounding use of excess fertilized material, such as non-implanted embryos, are considered in the fourth category of NRTs described below.

Donor insemination (DI) and surrogacy fall into the third category, where reproduction is separated from sexual intercourse and biological parenthood is separated from social parenthood. To the extent that genetic relationships are considered important, these NRTs may create uneasiness for some people. For example, it may be considered important to keep records of the biological parents for medical reasons, or even to ensure that biologically close relatives do not inadvertently mate. From a biological point of view, DI and surrogacy are related (in that both may result in a child with one biological parent who is different from the social parents). However, it must be recognized that surrogacy involves a greater commitment (physically, mentally, emotionally, and over time) by a donor, with all the possible psychological impacts.

The fourth category — which includes prenatal diagnosis — evokes questions surrounding abortion and the sanctity of life. Clearly, there are varying views on the appropriateness of aborting an affected fetus or on using embryo tissue for research.

The fifth category of NRTs — which includes gene therapy affecting the germ line — also raises questions about the long-term integrity of the gene pool.

Finally, this paper includes an extensive annotated bibliography available in the archives of the Royal Commission on New Reproductive Technologies. The review concludes that much of the existing literature draws upon an inadequate conceptual framework. These deficiencies become particularly important when considering NRTs.

In summary, this literature review makes the following suggestions:

1. decision making should be conceptualized as a shared process between individual and clinician;
2. individuals wish to be informed;
3. individuals probably wish to participate in decision making about their care, but probably not in problem solving;
4. most individuals need expert assistance to solve problems (identify and structure information) to make decisions;
5. necessary information includes medical factors plus social and psychological effects;
6. because this information may not be readily available, consensus-building efforts to determine, prepare, and disseminate such material should be helpful;
7. existing methods of outcome measurement are unlikely to be sufficiently sensitive to the quality-of-life concerns important to NRT-related decisions; thus, cost-utility analyses may be premature;
8. individual preferences will be most salient for those NRTs in categories 1 and 2, and thus models for selecting such medical treatments based on their effectiveness and their fit with patient wishes (e.g., decision analysis or technology assessment) should prove useful; and

9. individual preferences, although important, may not be the deciding factor for NRTs falling in categories 3-5; societal views and values must also be considered in making policy decisions about these issues, although such decisions may involve determining that NRT-related decisions should be left to the individual.

Part I: Introduction

Objectives

This literature review examines issues surrounding patient preferences in the area of reproductive health care, in particular:

1. patient preferences about information and participation in decision making;
2. the rules that patients perceive themselves using to make decisions; and
3. alternatives for measuring the values placed by patients on different outcomes (patient utility).

Premises

This monograph builds upon the Commission's research program. As such, it refers to, but neither defines nor concentrates upon, such questions as the costs and consequences of NRTs; the social, legal, and ethical frameworks; and the reasons given by individuals for using (or not using) them. These topics are covered elsewhere by the Commission.

NRTs may be analyzed in a variety of ways; however, this study begins with the premise that a decision maker must choose what course to follow. The literature reviewed is germane only if it is assumed that there are choices to make that should be based upon the decision maker's preferences and values. Recognizing that policy making involves making choices, however, does not necessarily imply that decisions should be based only upon getting maximum value for money.

Too often, focussing on cost containment leads to the assumption that decision makers must decide how to ration potentially useful resources. This focus on provider-oriented constraints, however, neglects the importance of understanding individuals' attitudes and wishes. Understanding the preferences both of individual patients and the public becomes crucial in terms of appropriate use of NRTs, an area in which both individual and societal decisions often depend on complex attitudes and values.

Language is a crucial way in which reality is shaped. Any policy analysis is shaped by the analyst's beliefs and values. Such values may be revealed, for example, by the term used to refer to an individual seeking health care services. "Consumer" or "client" implies a market relationship, while "patient" implies illness. No single term is optimal.

The following beliefs shape this analysis: (1) health care services should be allocated on the basis of need rather than on the basis of willingness (or ability) to pay — people should not receive unnecessary care nor be denied care that they need; and (2) any treatment offered should be appropriate, with a good chance of producing desired outcomes. Thus, the term “patient” rather than “consumer” or “client” is used throughout this paper.

Patients make choices that are termed “risky.” Particularly in Part III, this paper discusses medical treatments as gambles, that is, where the choice involves making decisions whose outcomes cannot be known with certainty. Each possible result is known as an outcome and the likelihood of a particular outcome is its probability. By definition, if all possible outcomes are designated, their probabilities must total 1. It is important to note that such jargon is not meant to imply that these outcomes are likely to be harmful or dangerous; rather, it recognizes that the outcome of a contemplated action (e.g., a fertility treatment) cannot be known with certainty. Some economic theorists distinguish between risk, which implies that probabilities are known, and uncertainty, which implies that they are not. This paper is based on the premise that probabilities are at best an estimate, which would apply with varying appropriateness to any specific individual; thus, the terms “risk” and “uncertainty” are used interchangeably.

This paper rejects a paternalistic view of the relationship between the patient and the health care provider. Patients should be active partners in deciding treatment; nonetheless, patients’ interests also must be balanced against those of society. The rejection of a market viewpoint carries with it recognition of the notion that society may decide that some demands will not (or should not) be met. Part IV considers the question of who should make decisions.

Outline of this Paper

What are the implication of these beliefs for policy making about NRTs? Policies concerning NRTs must consider several issues:

1. to what extent do patients *wish* to participate in making decisions about their own care? Can they be empowered? These questions relate to the *process* by which medical decisions are made;
2. what is a “good” outcome? How is it measured? These questions relate to the *outcomes* of the treatment decision; and
3. whose values and wishes should determine policy? Does this vary from issue to issue? These questions relate to the *context* within which a decision is made.

Whereas empirical evidence can cast light on the process and outcome questions, the context question is primarily a policy/value judgment. Thus,

this report reviews the literature relating to the first two issues and adds some comments regarding the third. Part II concentrates on the decision-making process, examining how patients make decisions, how they wish to participate in decisions about their own care, and how their preferences can best be incorporated into treatment choice. Part III addresses the issue of outcomes and their measurement. Part IV places these issues within a wider policy context, proposing a typology of NRTs and suggests issues that must be considered in making policy about them.

As a result of this review, it has been observed that much existing literature draws upon an inadequate conceptual framework. These deficiencies become particularly important when seeking to understand NRT-related issues. Thus, this review is supplemented by a critical discussion of some key issues and suggested theoretical modifications that may clarify policy decisions. These modifications are summarized below and described in detail in their respective chapters.

Part II Summary: Patient Preferences for Involvement and Information

This section examines patient preferences for involvement in decision making, focussing on patient values and attitudes towards such participation. In general, the literature suggests that patients do not want to participate in decision making, although they wish to be informed. However, much research makes insufficient recognition of the distinction between problem solving and decision making. Problem solving refers to the search for the single correct solution; thus, it requires expertise. Decision making refers to choices that require trade-offs among possible alternatives; thus, values and preferences must be considered. This review considers the role that patients wish to play in deciding their own care in light of this distinction. Among the questions examined are:

1. How much and under what circumstances do patients wish to be involved?
2. How do they make decisions?
3. How does the presentation of information affect their reactions?

The distinction suggests a greater role for experts in problem solving. Given problem-solving information, however, patients might be capable (and eager) to participate in deciding their course of action. In the case of NRTs, it has been found (David et al. 1988) that patients were more involved in making decisions about adoption than in making decisions about use of *in vitro* fertilization (IVF); the results appeared compatible with patients' belief that they needed more expert information on IVF, but that they understood enough about adoption to be able to make that decision themselves. Provision of the required information might facilitate a similar empowerment concerning IVF decisions.

Part III Summary: Measuring Outcomes

Part III examines alternatives for measuring the values placed by patients on different outcomes. Classical decision theory insists that outcome should be measured by a technique — derived from von Neumann-Morgenstern utility theory — that measures the utility an individual would assign to a particular outcome when various possibilities might occur. Ideally, this value is measured using a technique known as the standard gamble, according to which the value placed by an individual on an outcome is equivalent to 1 minus the risk of death that individual will accept to avoid living in that particular health state. This approach assigns little value to health states that are undesirable but not so horrible that one would rather be dead. This leads to such unappealing conclusions as “risk-averse patients must find chemotherapy less unpleasant than they say they do, since they are unwilling to accept much risk of death to escape its side-effects.” As a result, the von Neumann-Morgenstern utility index appears to be comparatively insensitive to differences in quality of life and comparatively sensitive to differences in life expectancy. Thus, risk-based (standard-gamble) methods of measuring patient values tend to understate the impact of interventions that improve quality of life. In addition, the standard gamble confounds the individual’s view of health with factors such as risk attitudes and time-preference pattern, and discounts years of life that will be gained in the distant future (Mehrez and Gafni 1991). This inherent systematic bias of the existing utility-measurement approach limits policy makers’ ability to use cost-utility approaches in allocating resources. The policy implications of this bias are particularly important in analyzing NRTs, since women unwilling to risk death to bear children still may value parenthood highly.

The use of what may be termed the decision-rule approach could permit disentanglement of the value placed on an outcome from the acceptable level of associated risk, thus allowing wider use of health-status measurement approaches (Deber and Goel 1990). The literature has been reviewed for ways of measuring patient outcomes, with particular attention to those that might be used to study NRTs.

Part IV Summary: The Context of the Decision

This section attempts to categorize NRTs, since grouping all NRTs under one umbrella term leaves unclear the extent to which individual preferences should dictate policy.

Category 1 of NRTs — including microsurgery — strongly resembles standard medical treatments. As Haimes (1990) pointed out, these do not challenge beliefs as to appropriate family structure. Like other medical treatments, they evoke questions of whether the benefit outweighs the risk or justifies the cost. Technology assessment, cost-effectiveness analysis, and decision analysis provide tools for studying this category of procedures, which may prove not worth doing under any circumstances, worth doing only if an individual will pay, or so valuable that society should provide

them. Issues surrounding payment and access to NRTs arise, as they will for other forms of therapy. The analysis is more complex for this category of NRTs than for other medical treatments only because risk and benefit must be evaluated for both mother and potential offspring. Since these procedures do not challenge societal values, however, choices may be analyzed primarily by considering values placed by individuals upon particular outcomes.

In addition to questions of risk-benefit and cost-benefit, category 2 NRTs — for example, IVF and DI by partner — add the question of separating reproduction from sex. This separation may have a great psychic impact on some people; however, it poses little threat to conceptions of family structure. In general, most societies tolerate this category of NRT, considering that individuals should decide these matters for themselves. Issues concerning use of excess fertilized material, such as non-implanted embryos, would be included in category 4.

DI and surrogacy fall into category 3. Here, not only is reproduction separated from sex, but biological parenthood is separated from social parenthood. To the extent that genetic relationships are important, these NRTs may create uneasiness for some people. For example, it may be considered important to keep records of the biological parents for medical reasons, or even to ensure that biologically close relatives do not mate. From a biological point of view, DI and surrogacy both may result in a child with one biological parent who is different from the social parents; however, it must be recognized that surrogacy involves a greater commitment (physically, mentally, emotionally, and over time) by the donor, with all the possible psychological impacts.

Category 4 NRTs, including prenatal diagnosis, evoke questions about abortion and the sanctity of life. Clearly, there are varying views on the appropriateness of aborting an affected fetus or on using embryo tissue for research.

Category 5 NRTs — comprising germ line gene therapy — also gives rise to questions about the long-term integrity of the gene pool.

It may be argued that individual preferences are most salient for categories 1 and 2, and models for selecting medical treatments based on their effectiveness and their fit with patient wishes (e.g., decision analysis or technology assessment) should prove useful. In addressing the other categories, however, societal views and values must also be considered. Individual preferences may not be the deciding factor.

Summary of Appendices

Appendix 1 is a glossary of key terms used in this review. Appendix 2 provides methodological details about the literature search and indicates the keywords used in this analysis. (An annotated bibliography of 378 books and articles selected for review is available in the archives of the Commission.)

Part II: Patient Preferences about Decision-Making Information and Participation

Women involved with NRTs have voiced their desire for increased participation. In a study by Hilary Graham and Ann Oakley on physicians' behaviour toward women in ante-natal clinics (Birke et al. 1990, 96), they noted that obstetricians and gynaecologists have — like other physicians — been severely criticized “for treating their women patients as incapable of actively participating in their treatment or making decisions, and thus failing to inform women sufficiently of the consequences of treatment or the options available to them” (ibid., 279). They suggested, “Counselling cannot by itself change the options that are open to women, but good counselling should provide women with enough insight into their own feelings and the realities of what is being offered to them that their judgements do not produce results very much at variance with their expectations” (ibid., 280-81). They also cited a U.K. study by Farrant (1985) that found insufficient information was provided to women undergoing prenatal diagnosis, which in turn reduced women's ability to make free informed choices (Birke et al. 1990, 179).

A similar desire for increased information and participation in decision making was expressed by those testifying to the Commission (*What We Heard — Issues and Questions Raised During the Public Hearings* 1991). Further questions must be asked about the increase in demands in recent years, the prevalence of such desire, and the feasibility of genuine participation.

Why Participate?

Ethics and the Roles of Physician and Patient

Historically, it has been assumed that it was the role of the physician, acting in the patient's “best interests,” to direct care and decide treatment (Brody 1989).

In bioethical terms, the moral principle pursued was *beneficence*. In this model, the patient's role was to comply with physician orders; a “good patient” would not question the physician's decision (Katz 1984a). This paternalistic approach assumed the patient and health care provider shared common interests and wishes, but only the physician had the expertise to determine what should be done. Accordingly, it was simple and appropriate for the physician to “spare” the patient the worry of decision making. Not only did this model leave little room for patient participation, but it argued that the physician was justified in under-informing or even deceiving a patient in the name of providing faith, reassurance, and hope (ibid.). In theory, this model considered patient preferences and values (as interpreted by the health care provider), but left the patient a minimal decision-making role.

In the consumer age, this model became increasingly unacceptable. An emerging bioethics literature suggested that other moral principles also were important. The following fundamental principles have been listed as those now accepted in medical ethics:

1. respect for persons (autonomy);
2. non-maleficence;
3. beneficence;
4. utility;
5. justice;
6. fidelity;
7. truthfulness;
8. disclosure; and
9. confidentiality (Childress 1989, 32).

What happens when these principles conflict? Many bioethicists have argued that *autonomy* must always prevail. Thus, the first set of proposed countermodels emphasized moving control over decision making from physician to patient. At one extreme — what Veatch (1972) termed the “*engineering model*” — the physician would be a technician and the patient the sole decision maker. In this view, health care providers would advise, while patients would make all decisions. Veatch’s *collegial model* recognized the imbalance of knowledge, and viewed patient and health care provider as full, equal partners.

These models have often been espoused by patient advocates; however, others argue that they are unrealistic. For example, Veatch rejected both alternatives to the paternalistic *priestly model* in favour of a shared *contractual model* (Brody 1989; see also Quill 1983). Indeed, North American genetic counsellors have adopted an ideology of non-directive counselling, explicitly recognizing the patient as the major decision-maker (Birke et al. 1990).

Although the term “contract” has been criticized as unrealistic and as tending to discourage a richer relationship, it appears to capture the germ of the current ideal: shared decision making in which both physicians and patients make contributions. In this model, physicians contribute their expertise in diagnosis and management, while patients contribute “personal moral values or lifestyle preferences” about which they “could be expected to know more than the physician could” (Brody 1989, 70). Selecting the optimal treatment thus requires the contributions of both the physician and patient (Brody 1980; Herman 1985; U.S., President’s Commission 1982; Gray et al. 1990; Lerman et al. 1990; Quill 1983; Weiss 1986).

Current bioethical thinking suggests that patient autonomy permits, and indeed requires, active participation by patients in making decisions about their own treatment. Shared decision making “requires

abandonment of the assumption, which is common in the medical ethics literature, that for most medical decisions there is an answer to the question, 'Who should decide?' The implications are profound: once it is no longer necessary for an individual to "own" the decision, emphasis can shift from a formal emphasis on rights to one based on sensitive communication (Whitbeck 1991, 53). This model places considerable attention on the need for clear, culturally sensitive, and effective communication (Rodin and Collins 1991).

Nonetheless, it must be recognized that the participatory ideal may encounter practical difficulties. These may include "potent, unconscious factors," such that patients may "need to be taken care of by powerful paternal or maternal figures" (Quill 1983, 233). Patients adopting the "sick role" may wish to revert to childlike behaviour; transference and countertransference may operate (Katz 1984a). The literature is divided as to whether respect for patient autonomy extends to allowing a patient to abdicate responsibility; however, most writers argue that patients must be educated and encouraged to act as adults. Other difficulties arise if patients are too ill to act as decision makers or if there is a need for rapid action. Still others result from the reality of busy clinical practice; physicians rarely have time to provide full information (Faden 1991; Beisecker and Beisecker 1990).

It should be stressed that, with the exception of not having enough time, these caveats rarely if ever apply to NRTs. Indeed, NRTs illustrate the clinical situation most suited to the participatory ideal. Potential users are sufficiently healthy to comprehend the relevant information and make decisions. The decisions are elective; that is, choices are available, and potential users have enough time to weigh their options. Most important, decisions about reproduction involve personal moral values or lifestyle preferences about which patients are more knowledgeable than their clinicians. For these reasons, the reviewed literature suggests that the paternalistic-expert model of decision making seems particularly inappropriate for NRT-related decisions.

Obtaining Participation

The existing medical structure may not encourage active patient participation. First, if patient consent is to be informed, a conducive environment must be established to make the patient feel independent and able to assist in making decisions, to ascertain the patient's goals and values, and to educate the patient about the risks and benefits of alternative treatment.

That active participation is possible has been shown empirically in studies by Greenfield and colleagues that sought to train patients to become empowered. In their first study (Greenfield et al. 1985), an experimental group of ulcer patients was presented with a treatment algorithm that clarified the medical process and identified necessary

decisions. These patients were coached to read their medical records, ask questions, and negotiate medical decisions during a 20-minute session before the scheduled physician visit. A control group of patients had a 20-minute session in which information about the cause, complications, and treatment of the ulcer disease were discussed, but they were not shown their medical records and not coached about asking questions. Audiotapes of the subsequent interactions between patients and physicians were analyzed.

Patients in the experimental group were significantly more involved in the interaction than were controls. They did not ask significantly more questions than the patients in the control group; however, they were more assertive in directing the flow of communication. In the control group, many interactions were one-way communications, in which the physician directed the interaction and the patient provided factual information. The researchers concluded that patients in the experimental group were twice as effective in obtaining information from physicians as patients in the control group.

The same researchers used a similar methodology in a study of diabetic patients. The experimental patients were guided to read their medical records and coached to ask questions, while the control group received the standardized educational package without discussion about their medical records (Greenfield et al. 1988). Again, the training proved effective in helping patients gain information.

Other study results have been less clear. Roter (1977) studied three groups of poor black women. One hundred women in an experimental group were coached by a health educator about how to ask questions. Another 100 women formed a placebo group; their session with the health educator focussed on ways to increase patient satisfaction and improve appointment keeping. Finally, 50 women in a non-randomized control group were administered only a satisfaction-attitudinal questionnaire following the clinic visit. Tape recordings of the physician-patient interaction during the following medical visit were analyzed for the placebo and experimental groups; all three groups completed the satisfaction-attitudinal questionnaire following their visits. Appointment-keeping rates for each group were computed retrospectively and prospectively from clinical records.

The research findings made it clear that conversations need two participants. The experimental group asked more questions and kept more appointments, but their interactions with the physician appeared characterized by more anger and anxiety than was observed in the placebo group. Patients in the experimental group also were less satisfied with the visit than their placebo counterparts. Similarly, Blanchard and colleagues found that patients who preferred to participate in decision making were slightly, but significantly, less satisfied than those who wanted the physician to make the decisions (Blanchard et al. 1988). Clearly, mere training in asking questions is insufficient if both the health care provider

and the patient do not expect that decision making should be shared. In that connection, it often has been claimed that clinicians see women — particularly poor women — as less capable of making decisions (Faden 1991). Trusting partnerships are difficult to build under such circumstances.

Another study analyzed whether patient participation could be increased through improving the efficiency of patients' comprehension (Robinson and Whitfield 1985). Three groups of patients were taped in conversation with their physicians and interviewed afterwards. Patients were given one of three kinds of written information: the Normal (control) group was informed only that the researcher was interested in how well the physician and patient understood each other. The Permission group received the same information as the Normal group, but also received explicit permission to ask questions of the physician. The Guidance group was "asked to imagine carrying out instructions, to notice any problems which might arise, and to raise these with the doctor." (Robinson and Whitfield 1985, 916). Frequency of questioning, patients' comments about treatment, and the accuracy of recommended treatment were coded.

There was no difference between the Normal and Permission groups in frequency of questioning and comments. This suggests that having health care providers state their willingness to answer questions may be insufficient to elicit genuine participation. The Guidance group, however, raised significantly more questions and comments and made fewer errors and omissions in their accounts of the recommended treatment.

Impact on Patient Outcomes

In theory, increased participation enhances the goal of patient autonomy and often has been supported for that reason alone; however, an even stronger case for greater participation may be made if it can be demonstrated that participation also improves outcomes.

In general, studies have concluded that encouraging patients to take a more active role in their care may indeed have instrumental payoffs in terms of improved outcomes (Brody et al. 1989a; Cassileth et al. 1980; Eghert et al. 1964; Eisenthal and Lazare 1976; Greenfield et al. 1985, 1988; Lerman et al. 1990; Levy and Howard 1982; Schulman 1979; Stiles et al. 1979; Wasserman et al. 1984; Wennberg 1990; Woolley et al. 1978). Patients who take this more active role may have better functional capacity and subjective well-being (Forrow et al. 1988). They also may have more effective physician-patient relationships (Speedling and Rose 1985).

The reasons for these improved results may relate to the patient's increased sense of control, which in turn has been suggested to improve outcomes. A sense of control seems to improve outcomes "by generating behaviours and attitudes that are health-maintaining" (Seeman and Seeman 1983, 156). Patients who have participated also are more likely to comply with treatment. In support of these conjectures, Cassileth et al. (1980) found that cancer patients who wanted to be involved in treatment

decisions were significantly more hopeful than those who did not. Greenfield et al. (1985) found that patients with peptic ulcer disease experienced better physical functioning with involvement in medical decision making. In their diabetes study, Greenfield et al. (1988) measured a series of outcomes, including control of blood glucose, functional ability, disease severity, and patient satisfaction, and concluded that patient participation has a beneficial effect on health outcomes and the patient's quality of life.

Participation where choices can be made may have detrimental effects, particularly an increase in anxiety. For example, Rothman (1987) noted that having to make an explicit choice can have a subtle effect on relationships. She suggested that amniocentesis may lead to "the tentative pregnancy," in which emotional attachment to the fetus is in effect conditional upon hearing favourable test results.

A study conducted by Christensen-Szalanski et al. (1987) postulated that increasing the amount of risk information provided to patients would increase their satisfaction with their care and alter their decision to circumcise their sons. Physicians asked 151 mothers about their desire to have their sons circumcised. The study found that the mothers' decisions were based on social, traditional, and religious reasons and largely ignored the medical information. In this study, physicians routinely informed all the mothers about a few of the most important medical complications associated with elective circumcision (partial disclosure). Half of these women also received a fully detailed list of medical complications associated with performing or avoiding circumcision (full disclosure). In addition, 14 mothers were given risk-related information verbally. No effect was found when mothers received only partial disclosure; however, mothers receiving full information felt less confident about the appropriateness of their decision. "The physician providing a comprehensive disclosure experienced more mental strain as a result of patients' subsequent feelings of antagonism, and experienced a potential loss of income with patients' not seeking return visits to the clinic" (*ibid.*, 864). The authors concluded that "because individuals differ in their desire for a comprehensive disclosure of medical complications associated with a procedure, and given that the disclosure of the information may do more harm than good or may inadvertently reduce patient autonomy, then perhaps one needs to alter the extent to which medical complications are disclosed according to each specific circumstance" (*ibid.*, 865). They suggested that physicians might want to present risk information during the prenatal visits, when the parents still may be undecided about circumcision.

It has long been recognized that health care providers have substantial control over patient decision making through control of information. Controversy has arisen concerning such issues as which side-effects must be disclosed to patients. For example, is it justifiable to worry a patient about an unlikely outcome? How can the beneficial effects of hope be maintained if patients are confronted with elaborate consent forms listing

many frightening but unlikely consequences of treatment? Will more harm be done than good? Will patients reject appropriate treatment?

Different balancings of beneficence and autonomy produce different answers. Katz noted that physicians admit among themselves that medicine is an inexact science and uncertainties exist (Katz 1984a); thus, he argued, physicians should be willing to admit these uncertainties to their patients. Katz suggested that pseudo-certainty may be psychologically easier for physicians and maintains the physician's control over the decision-making process; however, failure to acknowledge uncertainty is harmful to a trusting physician-patient relationship and undermines the capability of genuine mutual, shared decision making.

In the case of NRTs, clinicians would need to acknowledge the many related uncertainties, including those related to long-term safety (Rodin and Collins 1991).

Studies have found that patients are dissatisfied with the information they receive. Mathews (1983) suggested the communication of information may be more problematic because of the different frames of reference about what information should be shared, and the social distance between the physician and patient.

In general, the literature suggested that the relationship between patient participation and patient satisfaction is ambiguous. It is important to note that patient satisfaction is not necessarily related to a good outcome. Instead, evidence suggested that patient satisfaction may be more influenced by interpersonal factors in the physician-patient relationship (Ben-Sira 1976; Woolley et al. 1978; Speedling and Rose 1985).

Perhaps surprising those who espouse autonomy as essential to respect for patients, increased participation did not always lead to greater happiness. Examples included Roter's (1977) finding that encouraging patients to ask their physicians more questions resulted in lower satisfaction, or Greenfield and colleagues (1985) finding that participating ulcer patients were no more satisfied than the controls. These findings could have resulted if clinicians failed to respond satisfactorily to their patients' efforts; however, they also reflected a distinction noted by Ware et al. (1976) between the "art of care" and the "technical aspects of care." Most patient-satisfaction surveys suggested that "from the patient's perspective, the technical component is taken for granted, leaving the non-technical open to scrutiny and evaluation" (Speedling and Rose 1985). In a pilot test of their Perceived Involvement in Care scale, Lerman et al. (1990) found that, although there was a weak but significant relationship between self-reported patient involvement with decision making and satisfaction with their physician's technical competence, there was no correlation with the art of care. Thus, participation probably has a net positive effect but does not guarantee a happy, satisfied patient.

The strongest argument for patient involvement may be the discovery, through decision-analysis techniques, that optimal treatment in many clinical situations is not always immediately apparent.

McNeil et al. (1978) investigated the importance of patient attitudes toward survival in a situation involving the choice between surgical and medical therapy, where surgical therapy was seen as the optimal choice for life expectancy and 10-year survival rate, medical therapy seemed best on the basis of the three-year survival rate, and the decision was a "toss-up" on the basis of the five-year survival rate. Their evidence suggested that optimal therapeutic choice between two treatments depends on patients' attitudes toward the risk of surgery. For example, severely risk-averse patients should receive medical therapy, whereas mildly risk-averse or risk-neutral patients should choose surgery.

Under those circumstances, the value assigned to particular outcomes determines the optimal treatment (Barry et al. 1988; Fowler et al. 1988; Pauker and McNeil 1981; Wennberg et al. 1988). Thus, choice of therapy requires knowing those values, which in turn requires knowing the patient's wishes. Measurement of those values is discussed in Part III. From a procedural viewpoint, however, acceptance of this normative model of decision making requires either that the clinician become an excellent judge of patients' wishes, or that patients be allowed to participate. Otherwise, outcomes are likely to be sub-optimal, even judged from a purely technical standpoint.

Issues Concerning Patient Involvement

The issues concerning patient involvement may be divided into a set of related issues:

How much do patients wish to be *informed* about their diagnosis, possible treatments, and likely outcomes? These preferences vary, depending on how the information is presented.

To what extent do patients wish to be *involved* in their therapy, including making treatment decisions? Distinguishing between two elements of choice behaviour, decision making and problem solving, may clarify this distinction.

If the answer to the first two questions is "it depends on the patient," can patients who wish to participate be identified? How well are health care providers able to make those determinations?

How Much Do Patients Wish to Be Informed?

Most attention has been paid to the question of how much a physician should tell patients about their diagnoses and prognoses. Recognition of the extent to which patients' mental attitudes and hope can influence outcomes led many physicians to argue that it was inhumane and perhaps unethical to tell a patient that there was no longer hope for a cure. This view saw the ethical principle of beneficence as dominating; patient information and choices would be manipulated "for their own good." Others argued for telling patients the truth under all circumstances, both on pragmatic grounds (a deceived patient is less likely to be compliant) and out of ethical repugnance of violating a patient's autonomy (e.g., Katz

1984a). Recently, as noted, medical ethicists argued strongly that autonomy always should outweigh beneficence; thus, patients should be informed, whether they want the knowledge or not.

Empirical studies on these issues generally concentrated on "life-and-death" issues, such as whether a patient should be told that an illness is likely to be fatal. These findings must therefore be extrapolated to NRTs with caution.

Changing views on truth telling can be seen in the results of two studies of physicians' attitudes toward disclosing a cancer diagnosis to patients. In a widely cited 1961 paper by Oken, it was found that 90 percent of 219 physicians surveyed did not inform the patient of the diagnosis. The rationales for such disclosure policy cast doubt on whether the physicians had established their policy to meet patient wishes or because they were uncomfortable discussing failure of treatment (or death) with their patients. Later, Novack et al. (1979) administered the same questionnaire to 600 university-affiliated medical staff. Their findings indicated a reversal in opinion, with 97 percent of the 264 respondents now preferring to inform cancer patients of the diagnosis. The results may have reflected a diminished stigmatization of cancer and a greater awareness of its signs and symptoms; that is, cancer may no longer have been seen as a death sentence, and physicians may therefore have been more comfortable discussing it with patients. It seems likely that this change also reflected the rise in patient empowerment and increasing public scrutiny of the medical profession (Henriques et al. 1980).

Recent anecdotal evidence of the current unacceptability of physician deceit in the area of NRTs may be seen in the recent trial of Dr. Cecil Jacobson, who was convicted on 52 counts of fraud and perjury for lying to women in the late 1970s and early 1980s about the identity of the sperm donor used in their DI procedures. (He used his own semen.) Jacobson's defence that "I spent my life trying to help women have children. It's a shock to be found guilty of trying to help people," and his lawyer's claim that he "had been very successful in helping many high-risk women become pregnant and give birth to healthy babies" were rejected.

The argument that Jacobson's behaviour violated his patients' rights to privacy and to be fully informed about their treatments was correctly seen as the key issue. Jacobson now faces up to 280 years in prison and \$500 000 in fines (Cimons 1992). These findings will influence information disclosure more generally in fertility clinics. Indeed, to the extent that a child resulting from NRT procedures is also a "patient," the issue of whether DI offspring have the right to know their genetic parents is likely to arise. As non-disclosure comes under increasing pressure, more information will be desirable.

What Do Patients Want to Know?

The ethical consensus now has shifted, and physicians appear more open to disclosure of diagnostic information. But what do patients want to know, and what do they hear? A variety of studies (Cassileth et al. 1980; Blanchard et al. 1988; Greenfield et al. 1988; Lerman et al. 1990; Strull et al. 1984) examined patients' desire for information.

Cassileth et al. (1980), whose study surveyed 256 patients who had cancer, were among the first to explore the degree to which patients prefer to become informed and involved in their medical care. Their research items, although never formally validated, have been influential among other researchers. The *participation* item asked the respondent to select one of the following statements: "I prefer to leave decisions about my medical care and treatment up to my doctor" or "I prefer to participate in decisions about my medical care and treatment." The *information* item asked patients to select one of the following statements: "I want *only* the information needed to care for myself properly"; "I want additional information only if it is *good* news"; or "I want as *much* information as possible, good and bad."

The patients also were given a checklist of 12 specific items of information and asked to indicate whether they "absolutely need," "would like to have," or "do not want" each piece of information.

Cassileth et al. found that "the younger the patients, the more closely they conformed to the well-informed-participant standard of patient behaviour; the older the patients, the more likely they were to prefer the older, non-participatory-patient role." The vast majority of patients, however, regardless of age, indicated they wanted all possible information, good or bad. Eighty percent of those over age 60, and 96 percent of those aged 20 to 39 years of age, selected "Want all information — good and bad" as opposed to "Want only minimal or good information." More than 90 percent of patients needed or wanted all except the most negative of the 12 specific examples (that is, "examples of cases where treatment was ineffective") and only 21.9 percent said they did not want to know such facts. Similar conclusions could be drawn from other studies (e.g., Blanchard et al. 1988; Greenfield et al. 1988; Lerman et al. 1990; Strull et al. 1984) discussed in this part of the review.

The physician's image of a childlike patient who would prefer to be sheltered from harsh truths clearly is unsupported by the literature. It appeared that most patients desire information, although an identifiable proportion do not.

How Does the Presentation of Information Affect Its Comprehension?

To be understood, information must be presented in a way that is appropriate to the patient. Format, content, and timing of the material clearly are important; however, this chapter has not reviewed the literature concerning effective communication.

The literature indicated that expressed preferences may be influenced by the way options are framed. This literature is discussed in Part III.

To What Extent Do Patients Wish to Be Involved?

Some writers discussed participation using a vocabulary that envisioned continued physician control with more extensive patient input. Others wrote of shared decision making (Wennberg 1990). At the other end of the language continuum, still others wrote of control. Research examined whether patients support the theoretical challenges to paternalistic models and what role they wish to play in decision-making about their own care.

A case for participation was made in Cassileth's pioneering study. The participation item in this study of 256 patients with cancer indicated that 87 percent of patients 20-39 years of age, 62 percent of those aged 40-59, and 51 percent of those older than age 60 preferred to participate in medical decisions; however, the term "participate" was not defined and, as noted below, patients appeared to attach various meanings to it.

Similarly, Larsson et al. (1989) surveyed 666 Swedish patients awaiting an operation about their involvement in the decision to operate. The questionnaire, sent one week before the operation, covered various issues. The findings showed that 41 percent of the patients regarded the decision to operate as a joint physician-patient decision, 8 percent as their own decision, and 29 percent as the physician's advocated position. Although 73 percent responded that they had been involved in the decision making "as much as they wished," the authors stressed that "patient satisfaction can just as well be understood as resulting from low expectations with respect to one's own influence" (ibid.).

Indeed, a sizable proportion of the sample reported being not fully convinced that operating was the correct decision. Common reasons given were: fear of complications, worry about the operation, and anaesthetic procedures.

Some inference as to desire for information and involvement can be drawn from surveys of the satisfaction of IVF patients, which also suggest that patients wish to be informed. For example, Sabourin et al. (1991) surveyed 385 couples who completed a series of questionnaires on their first clinic visit. Two hundred and five couples completed follow-up surveys 6 and 12 months later. The instruments included (1) a patient satisfaction form to assess consumer satisfaction with fertility treatment; (2) a Psychiatric Symptom Inventory to measure the presence of common psychiatric symptoms; (3) the Rosenberg Self-Esteem Scale to capture feelings about the self; (4) the Psychological State of Stress Questionnaire to evaluate the degree of stress experienced; (5) the Dyadic Adjustment Scale to measure marital satisfaction; (6) the Index of Sexual Satisfaction to measure current level of sexual satisfaction; and (7) the Social Support Questionnaire to assess the satisfaction with support received.

Generally, the couples were satisfied with fertility treatments; however, they reported less satisfaction with the information received about medical treatments. Ten percent of the couples said they were dissatisfied. The researchers noted "patients seem to resent the lack of information about

the prognosis, the small quantity of time spent discussing medical and personal issues with the doctor, the numerous hours spent waiting for medical staff, the high number of different medical doctors they meet, and the lack of information concerning alternative solutions to the fertility problem" (Sabourin et al. 1991, 1084). Patients who indicated personal, marital, and social symptoms of distress at the beginning of the program were more likely to be dissatisfied with the fertility treatments.

In a small (and not particularly rigorous) study of 20 women, Alder and Templeton (1985) drew similar conclusions about inadequate opportunities for adding questions and discussion during treatment. Sixty percent were not fully satisfied; five of the 20 would have preferred counselling with a non-medical person, and more than half would have liked discussions with other women receiving IVF.

Subsequent studies tried to distinguish between a desire to be *informed* and a desire to be *involved*. For example, Strull et al. (1984) surveyed 210 patients with hypertension, as well as 50 of their personal physicians. They found that 41 percent of the patients preferred more information about hypertension. Fifty-five percent of the patients preferred to know "quite a lot" of information or "all there is to know" about hypertension. When asked, "Who do you think should make the decisions about medicines for treatment of high blood pressure?", 47 percent of patients said the clinician should make the therapeutic decisions "using all that's known about the medicines." One-third of the patients preferred that the clinician "should make the decision but strongly consider the patient's opinion," while only 19 percent preferred shared decision making. Another important finding of the study, which will be discussed below, is that the physicians studied were poor judges of their patients' decision-making preferences.

In a study by Blanchard et al. (1988), 439 interactions between cancer inpatients in a large teaching hospital and their physicians were observed in an effort to increase understanding of the relationship between physician behaviour and patient satisfaction. Trained observers measured the behaviour of physicians during their morning rounds. The extent to which the patient appeared to be engaged with the physician and the extent to which the patient asked questions were measured. Following the completion of rounds the observer returned to ask the patients about their satisfaction.

This study, which used the Cassileth information and participation measures, found that 92 percent of the patients wanted all information, good or bad. Only 69 percent, however, preferred to participate in medical decisions.

Interpretation of these findings is complicated because the unit of analysis was the encounter rather than the patient. Most analysis was based on 402 interactions — representing 89 patients — in which the patient indicated he or she wanted all information. It may be argued that this analytical decision represents an unwarranted inflation of sample size (and hence of statistical significance), particularly if patient preferences for

information and participation remain relatively stable. Nonetheless, the researchers concluded that although almost all patients want information, there was a "small, but important group of patients who do not prefer to participate in decision making, although wanting all information." They suggested that "patient preferences be respected and that the physician respond to those preferences" (Blanchard et al. 1988, 1144).

In a Canadian study, Llewellyn-Thomas et al. (1991b) adapted the Cassileth and Strull measures into a five-point scale, which they subsequently collapsed in an analysis of the attitudes of 60 cancer outpatients towards clinical trial entry. Thirty-two of the 60 patients had a preference for participating; that is, they indicated, "The *doctor and I* should make the decisions together on an equal basis;" "I should make the decisions, but strongly consider the doctor's opinion," or "I should make the decision using all I know or learn about the treatments." The other 28 patients adopted a physician-dominant style, indicating either, "The *doctor* should make the decisions using all that's known about the treatments," or "The *doctor* should make the decisions but strongly consider my opinion." The authors noted that the participation-oriented group was less likely to agree to enter a hypothetical clinical trial. They suggested that this might have been seen as giving away treatment decision making to the physician (ibid., 39).

The preferences of Canadian cancer patients concerning roles in treatment decision making also were examined by Degner and Russell (1988). They postulated that people with cancer adopted "ideal points" along the psychological dimension of control over decision making, which they believe spanned a continuum from keeping, to sharing, to giving away control over decision making. They tested 60 cancer patients from a Winnipeg clinic using two card-sort procedures to select from eight hypothetical vignettes that described patterns of control over treatment decision making. Fifty-nine of the 60 patients reacted consistently with their underlying psychological dimension of preferences for control. The study found that most patients surveyed preferred shared control, and they would rather give control to the physician than to a family member.

In a study examining the relationship between patient participation and health outcomes, Brody et al. (1989a) categorized patients as active or passive based on their responses to the question, "What role do you want to play (or did you play) during today's visit?" The patients could select among four possible roles: (1) The doctor takes (took) the initiative and decides(d) what is (was) best for me; (2) the doctor considers(ed) some of my ideas but still makes (made) most, if not all, of the final decisions; (3) the doctor and I make (made) the final decisions together; or (4) I make (made) all of the final decisions" (ibid., 507).

The researchers defined those selecting roles 1 or 2 as passive patients and those selecting roles 3 or 4 as active patients. Health outcomes were evaluated on the basis of self-reported levels of discomfort and dysfunction measured before and one week after the medical visit. Patients' attitudes

about their illness were measured using "concerns about medical problems." The scale assessed "how serious patients felt their medical problems were; how concerned they were that these problems would lead to other problems; and how concerned they were that these problems would last a long time or recur." Perceived personal control over medical problems was measured by a Likert-style question. Patients' satisfaction was measured one day after the medical visit using a modified version of the Ware Satisfaction Scale (Ware et al. 1976).

The results confirmed the hypothesis that patients who believed they played a more active role in their own care would have a greater sense of control over their health and be less concerned about their illness following a medical visit. Almost half of the patients reported that they played a more active role; these active patients tended to be satisfied with their physicians, had lower levels of illness concerns, and had a greater sense of control over their conditions than the passive patients. The overall medical condition of active patients also improved more than that of passive patients.

Ende et al. (1989) designed a questionnaire to capture the distinction between the desires for information and participation. The patient's preferences for information and desire to participate were elicited using the Autonomy Preference Index, comprising an eight-item scale on information seeking and a fifteen-item scale on decision making.

They concluded that patients had a strong desire to be informed but only a weak desire to make decisions. There was no correlation between patients' information-seeking preferences and decision-making. The more severely ill the patient, the less likely he or she desired to participate in decision-making. The findings suggested that decision making and desire for information may not be linked.

The relationship between patients' desire for information and their preference for participation in decision making also was examined by Sutherland et al. (1989). Fifty-two patients who had cancer were administered a series of questionnaires to assess how actively they sought information regarding their health status. Three instruments were used to elicit patients' responses: (1) the Health Opinion Survey, measuring preferences for information and involvement in care; (2) an 18-item linear analog self-assessment (LASA), eliciting information-seeking responses; and (3) an adapted version of the Strull et al. (1984) items on patient preferences for participation in their care under "ideal" circumstances.

About 77 percent of patients reported that they had participated in decision making to a desired extent. Most other patients (23 percent) preferred an opportunity for greater input. As in the Ende study, many patients actively sought information, but a majority preferred the physician to be the primary decision maker. The researchers concluded that "professionals, in an attempt to encourage informed, autonomous decision making, may provide information which many patients may indeed desire

to have" (Sutherland et al. 1989, 263), but it must be remembered that patients still may desire the physician to make the decision.

Beisecker and Beisecker (1990) examined patients' information-seeking behaviour when communicating with doctors. Physician-patient interactions involving 106 rehabilitation-medicine patients in an outpatient clinic were studied. These patients filled out a sociodemographic questionnaire while awaiting their physicians, had their consultation with their doctor audio taped, were interviewed immediately after the appointment, and were asked to complete an opinion survey 10-14 days later. Measurements were taken on (1) the Desire for Information Scale, which asked, "How important is it to you to be given information in the following areas." Respondents replied on the basis of "1 = not at all important" to "5 = very important," for 14 designated items, the results of which were totalled; and (2) the Locus of Authority Scale, which asked, "Following are some areas in which decisions are made in medicine. Who do you think should make the decisions in each area: doctor, patient, or both doctor and patient?" for 13 specified items.

The results agreed with those of Blanchard et al. (1988). Patients wanted information; indeed, there was little variation (the average score was more than 4.6 on the five-point scale, with more than 90 percent of patients scoring more than 4 and 31 percent scoring 5). Patients indicated, however, that they believed most decision-making authority should rest with physicians. A striking finding was that the overwhelming desire for information was not always reflected in "information-seeking communications in the doctor-patient interaction"; indeed, 30 percent of the 106 patients did not seek information (*ibid.*, 24).

The researchers acknowledged that patients with chronic disabilities — the population studied — might be less likely to follow through on their questions than other patients, but they stressed that situational factors surrounding the physician-patient interaction better explain patient information-seeking behaviours than do patient attitudes, demographic variables, or even the physician seen. They noted, "Patients take cues about appropriate role behaviour from doctors and others with whom they interact. The diagnosis, reason for visit, and time constraints may influence these cues and, by doing so, may influence the patient's communication behaviour" (Beisecker and Beisecker 1990, 27). They devoted particular attention to the length of the interaction, noting that "short interactions minimize patient question asking and expression of patient attitudes" (*ibid.*, 28).

What Patient Characteristics Explain Differences in the Desire to Participate?

The literature concluded that patients who want a more active decision-making role are characterized by a "complex relationship between the variables of age, degree of illness and the presence of the 'significant other'" (Blanchard 1988, 1144).

As several studies have concluded, age appears to be the most important predictor of preferences for participation in decision making, with younger patients desiring greater involvement (Cassileth et al. 1980; Strull et al. 1984). Empirical evidence also suggested that better-educated persons may prefer greater involvement in decision making (Cassileth et al. 1980; Siminoff and Fetting 1991; Strull et al. 1984; Wartman et al. 1983). Those with more severe illnesses may prefer not to participate in their medical care (Ende et al. 1989; Strull et al. 1984). Blanchard et al. (1988) concluded that those who preferred to leave decisions to physicians were primarily older, more severely ill men, almost all of whom were married. They suggested that these patients had become dependent on their spouses and physicians.

Because they are younger and not severely ill, NRT-related patients may be expected to have a strong preference for participation in decision making.

What Is to Be Done?

Sensitive Paternalism and Informed Consent

At first glance the research evidence, although mixed, would appear to suggest that few patients wish to participate (Beisecker and Beisecker 1990; Blanchard et al. 1988; Degner and Russell 1988; Ende et al. 1989; Greenfield et al. 1985, 1988; Lerman et al. 1990; Strull et al. 1984; Waterworth and Luker 1990). If these findings are correct, what are the policy implications?

One possibility is to abandon the shared-decision-making ideal. It may be argued that paternalism can be retained, as long as the physician becomes more sensitive to the patient's problems and concerns and, hence, becomes a more effective agent.

Faced with evidence that many patients do not wish to participate, some authors have concluded that respect for patient autonomy required a return to *sensitive paternalism* (Weiss 1985). For example, Waterworth and Luker (1990) conducted structured interviews with 12 patients about their perceptions of involvement in decisions concerning their own treatment and nursing care. On the basis of this small, unrepresentative sample using invalidated instruments, they concluded that patients wished to "toe the line" and please the nurse. They argued that if nurses encouraged patient involvement, they might be coercing patients to comply with their wishes. They stated that patients should not be forced to assume a collaborative role, and that promoting individualized care is not synonymous with active patient involvement. An unusual (and disquieting) aspect of this article was its persistent, traditional resistance to patient empowerment in the guise of a beneficent-provider orientation within a profession — nursing — that had emerged as a strong patient advocate. Presumably, some health care providers still see patient empowerment as a threat (Katz 1984a).

In most cases, this new paternalism was accompanied by a recognition that patients wish to be informed and, therefore, should receive better information than had traditionally been the case. This model may be termed *informed consent*, implying that the clinician proposes a course of action over which the patient has veto rights.

As currently practised, informed consent has many practical difficulties, some of which were investigated by Lidz et al. (1983). These authors argued that the legal doctrine of informed consent fails to deal with the realities of medical decision making. Medical decisions are rarely based on a single episode; usually, they develop from processes that evolve over time. This statement is particularly true for NRTs, which often exemplify a phenomenon in which one step leads, seemingly inexorably, to the next. Thus, procedures must deal with an anticipated course of treatment, rather than a single procedure or event.

Lidz et al. (1983) also noted the importance of patient attitudes in allowing genuine patient participation. In this study, observers studied two inpatient wards and a surgical outpatient clinic. Observers studied patient-staff interactions and interviewed patients.

Many patients believed that decisions about treatment are the physician's responsibility. Although it was noted that patients often want information, this could be for reasons such as facilitating compliance with treatment, as a sign of courtesy, or exercising a veto over a previous physician decision. Only 10 percent of the patients played an active decision-making role. It was found that inpatients were less likely than outpatients to question physicians or take an active role in decisions. Patients with chronic disease usually were more actively involved (attributed in part to their greater experience with the health care system). The investigators concluded that the legalistic approach to informed consent — relying upon carefully worded consent forms — was inferior to a process that would encourage genuine patient participation.

Timing is among the key factors in encouraging genuine transmission of information. As traditionally implemented, informed consent may be ineffective if patients are under too much emotional stress to digest the information provided. Wade (1990) studied cholecystectomy patients; all received preoperative counselling followed by a questionnaire concerning the surgical procedure, risks, possible complications, and the need for post-operative self-care. Before and after surgery, the patients also were administered a mood questionnaire concerning degrees of emotion. Several weeks after discharge, the patients were mailed a questionnaire concerning the counselling they had received.

Initially, a majority of patients (90 percent of 144) correctly identified the risk of death resulting from elective cholecystectomy; however, at discharge, more than half of those patients (54 percent of 124) reported that they had not been informed that death could result. Preoperative pain, emotional distress, and medication were not associated with lack of recall of disclosure of risk. Wade advised physicians to obtain consent in writing,

to provide comprehensive counselling, and to be particularly aware of confused patients and those with complications.

Nonetheless, the legal notion of informed consent still does not leave the patient as an active partner in care, and cannot achieve the potential benefits deriving from an informed partner who understands and sets treatment goals. It should be stressed that there is a subtle but important distinction between the legal notion of informed consent and the ideal of shared decision making. This distinction resembles, but exceeds, that drawn between informed consent and informed choice for the Commission.

Informed consent ... is geared only toward eliciting consent for a specific medical procedure. Informed choice places medical procedures in the context of wider social choices, such as adopting, becoming foster parents, or remaining without children. (Canada, Royal Commission 1991, 11)

This definition of informed choice merely calls for better provision of information and a better depiction of the available choices; however, informed choice requires a genuine partnership. As the Commission's report also noted, "Many people who appeared called eloquently for a mutually respectful partnership between physicians and patients that will allow consumers to make their own informed choices" (Canada, Royal Commission 1991, 11).

Birke et al. (1990, 290) also noted that "informed choice has to mean that doctors should inform, but not decide." They observed, "To make such decisions, people need to know what the alternatives are and the likely effects of each option; if doctors do not know the answers, they should share the extent of their ignorance as well as their knowledge with the people they might treat" (ibid., 290-91). Clearly, such information must include social as well as medical consequences. But how can this ideal be made compatible with the research evidence presented above?

How Well Do Health Care Providers Know What Patients Want?

Advocates of sensitive paternalism have found it discouraging that the literature suggests physicians are poor judges of what their patients wish to know (Strull et al. 1984) or do. In the McNeil et al. (1978) study of lung-cancer patients, for example, most clinicians were unaware that certain of their patients would prefer radiotherapy to surgery.

Physicians may also be poor judges of the extent to which their patients wish to be involved. For example, Strull et al. (1984) noted that physicians underestimated their patients' preferences for discussion about therapy in 29 percent of cases and overestimated them in 11 percent of cases. Although 53 percent of patients surveyed preferred to participate in their treatment, clinicians believed that 78 percent desired to do so. The investigators concluded that clinicians are poor judges of patient preferences about decision making, thinking that more wished to participate than actually did, and that there is no substitute for asking patients directly about their preferences.

If sensitive paternalism is rejected (as it probably would be on legal and ethical grounds), what are the alternatives? One alternative is to conclude that patients in the studies reviewed were misinformed and needed to be educated to want more autonomy.

Another alternative, however, is to suggest that research evidence has been misinterpreted. While some patients may wish to retain a passive role, confusion may have arisen in interpreting these studies because "participation" has been poorly defined. Two dimensions of choice — decision making and problem solving — may have been confused. Making this distinction can assist in clarifying possible roles for patients and clinicians (Baumann and Deber 1989).

Decision Making and Problem Solving

Baumann and Deber defined *problem solving* as the search for the single, "correct" solution to a problem. In contrast, they defined *decision making* as making choices — often requiring trade-offs — among available alternatives.

The key distinction for medical choice is that the values assigned to different potential outcomes are irrelevant to problem solving. It does not matter whether one wishes an X-ray to show that one's leg is not broken any more than whether one wishes two plus two to equal seven. There is only one correct answer, and the issue is whether one has the skill, knowledge, and luck to find it. Thus, problem solving requires the problem solver to possess sufficient knowledge and problem-solving skills to identify alternatives and the probability of each outcome, but it has a limited role for patient or public involvement.

Knowing the alternatives does not dictate what action to take. If one must select from among possible courses of action, information about how different outcomes are valued becomes crucial. Thus, decision making may be seen as going beyond problem solving (Deber and Baumann 1992), requiring problem-solving skills, knowledge, and clear values. Only when faced with decision-making tasks must one ascertain values and preferences. Partitioning the choice into its problem-solving and decision-making components thus highlights the points at which patient participation is crucial.

For example, in a study of decision making for symptomatic prostatism (Barry et al. 1988), patients had to choose a watch-and-wait strategy, with an implied continuation of sub-optimal health, or surgical transurethral resection of the prostate (TURP), with a varying probability of symptom improvement and a small risk of death. The researchers (ibid) found that the utility patients received from TURP depends on the utility ascribed by patients to life with symptoms of prostatism. If the latter is perceived to be poor, surgery is the preferred treatment. Patients bothered less by these symptoms of prostatism than by the potential complications of surgery might prefer watchful waiting or medical therapy. Clearly, the optimal therapy choice is a decision that depends upon the patient's preferences for

non-monetary outcomes. It requires prior analysis by experts to inform the patient of available choices, provide the necessary probabilities, and indicate which of the patient's utilities must be assessed.

The decision-making/problem-solving distinction is relatively recent and is only now being tested empirically (Deber et al. 1993); however, as shown below, it is compatible with many reported findings.

The contractual model can be seen to be based in part on this distinction. It may be argued that this model assumes the physician has responsibility for problem solving, but decision making should be shared between doctor and patient. Similarly, Kassirer (1983) wrote about "usurping patients' prerogatives." His paper, which stressed the importance of "patient participation," noted the difference between probability (information that the physician provides) and utility, which must be assessed by the patient.

Studies reviewed for this paper suggesting that patients do not wish to be decision makers did not note this distinction (Beisecker and Beisecker 1990; Blanchard et al. 1988; and Degner and Russell 1988). In attempting to interpret these studies, it is unclear to what extent patients rejected a role in *problem solving* as opposed to rejecting involvement in decision making.

In this connection, it is important to distinguish the rationale for involvement presented above, which requires patient involvement in decision making but places initial responsibility for problem solving with the clinician, from some claims of the patient-rights movements, which define full involvement as including an active patient role in problem solving as one way of lessening medical dominance.

The New Our Bodies, Ourselves (Boston Women's Health Book Collective 1984) is a clear example of efforts to educate women about their own anatomy; women's health collectives taught women to perform their own internal examinations. Similarly, feminists may call for women to perform their own DI. It is important to distinguish patient preferences for non-participation in such problem solving from patient unwillingness to participate in making ultimate decisions.

Cassileth did not use this distinction; however, it is noteworthy that some of his participation-oriented patients expressed a wish to be involved in problem solving, rather than just in making treatment decisions. He quoted them as remarking, "It's my body and my disease"; "You have to take responsibility for your own body"; and "I want to know everything so I can help take care of myself." Similarly, Cassileth's non-participating patients may have rejected that role, rather than involvement in weighing their own values and selecting among treatment alternatives. They said, "The layman is not qualified to make decisions"; "I am not qualified"; and "It's the doctor's job; he'll take care of the details." It must be asked whether such patients would remain unwilling to participate if provided with the necessary information and support in deciding what alternative they would prefer, taking into account their own values for different health

outcomes. Only one of the remarks quoted by Cassileth could be seen as a rejection of decision making: "I need as little to worry about as possible."

Ende et al. (1989) concluded that "patients prefer that decisions be made principally by their physicians, not themselves, although they very much want to be informed." This conclusion could have a similar explanation. These researchers inquired about questions such as "whether a cardiologist should be consulted" if a patient were discovered to be having a heart attack — decisions for which patients, not surprisingly, felt a need for expert input.

In Beisecker and Beisecker (1990), the Locus of Authority Scale also included items of a problem-solving nature, such as what information to cover in a patient's medical history, which drug and drug dosage to use, and whether a patient should undergo diagnostic tests. Unfortunately, the paper did not isolate the responses to the few items identifiably oriented toward decision making, such as how much to tell or involve a patient's family, or what treatment alternatives to use (e.g., surgery vs. other therapy).

Additional evidence that many patients desire shared decision making was revealed in a Harris poll cited by Ende et al. (1989), which indicated that 72 percent of patients surveyed preferred that "the doctor discusses alternatives with the patient and the two of them decide together how to proceed" rather than unilateral control by either party.

Conclusion

This paper postulates that most patients prefer to have experts perform problem-solving tasks but desire an active decision-making role. If accurate, this implies that health care providers play an important role in analyzing and structuring information for patients and assisting them in clarifying their own values to make informed choices.

This conclusion seems compatible with the findings of the Commission's public hearings (Canada, Royal Commission, 1991). Dominant themes of that testimony included the need for better information and a "mutually respectful partnership between physicians and patients" that will allow health care users to make informed choices about their own treatment.

This literature review and the Commission testimony suggest that NRT-related decisions meet the ideal conditions for patient partnership in clinical decision making. For such partnership to occur, patients require sufficient information to make full, informed choices. At a minimum, this would require clarification of: (1) the available alternatives; (2) the potential outcomes for each alternative; (3) the costs, risks, and benefits of each alternative; and (4) the values attached by the patient to each potential outcome. Clinicians have a key role to play in ensuring that such information is available and understandable.

Part III: Measuring Patient Preferences for Potential Treatment Outcomes

Introduction

Shared decision making between patient and health care practitioner seems particularly appropriate when dealing with NRTs. How can patient preferences be incorporated into decision making, and how can such preferences be measured?

A rational decision may be defined in terms of the process followed (e.g., as a decision reached through a reasoning process) or in terms of its results (e.g., that it maximizes the chance of achieving an outcome consistent with the decision maker's values and preferences). This part of the paper describes a theory of rational decision making known as *decision analysis*, which purports to describe a process that — in the long run — yields the best chance of obtaining optimal results. The paper then notes barriers and what the literature terms *heuristics* which may interfere with the problem-solving aspects of rational choice. It is noted that these barriers strengthen the case for developing systematic mechanisms for educating and informing patients about their choices.

The paper also discusses the decision-making aspects of choice; that is, assessing the individual's values and preferences. It describes decision theory, which requires that the utility attached to each possible outcome must be measured. Finally, the paper indicates difficulties with the currently used measurement strategies and suggests possible alternatives.

This paper also discusses some studies that have examined the attitudes of infertile couples, health care providers, and the public toward NRTs.

Theories of Rational Decision Making: Decision Analysis

Often, choice may be improved by employing quantitative tools to structure problems and assist in analyzing them. *Decision analysis*, also known as *expected utility theory* (EUT) or *subjective expected utility theory* (SEUT), is the standard method of analyzing how people make risky choices (Hellinger 1989). Decision analysis structures the choice into *choice nodes* (under the decision maker's control) and *chance nodes* (which depict the outcomes that might result from each choice). This structure often is presented as a *decision tree*. For example, in a medical decision, the choice node might first be whether or not to perform surgery, while the chance nodes are the possible outcomes (e.g., death, major or minor morbidity, or perfect health). In the terms used in this paper, identification of this structure would be a problem-solving exercise.

The decision maker next determines the *conditional probability* of each possible outcome at that chance node. Again, identification of the relevant probabilities would be a problem-solving exercise. He or she then assigns

a *utility* value (measured on a scale of 0 to 1) to each outcome. Identification and use of these utilities is crucial to decision making.

A *decision rule* is then used to select the best choice. In the terms used in this paper, selection of the decision rule involves decision making, because it depends upon the decision-maker's preferences (e.g., the attitude toward risk). Once the rule is chosen, however, applying it to select the best course of action is a straightforward computational exercise (that is, a problem-solving task). This distinction has been blurred by most decision analysts, since they usually rely upon only one decision rule: *maximize the expected utility* (MEU). MEU requires the analyst to multiply the probability of each occurrence at each chance node by its utility, total the resulting values, and select the branch with the highest numerical total. (For a clear description of MEU applied to medicine, see Weinstein and Fineberg 1980.)

Thus, classical decision analysis assumes that individuals will maximize expected utility; the MEU model often is referred to as the *normative* model of decision making. In contrast, a *descriptive* model would explain how people actually make decisions.

Research has established that this decision analytic model (also called the rational model) provides a poor description of how people actually behave (Hellinger 1989; Machina 1987; Schoemaker 1982; and Slovic and Lichtenstein 1983); however, its proponents are undeterred. They believe that choices could be improved if people could be trained to follow the model when making decisions. Accordingly, normative-model advocates may design educational programs to train people to use decision-analytic approaches. Although some assumptions associated with these models may be criticized, it should be noted that a decision analysis can be useful in structuring information to assist people in making choices, particularly if attention is paid to the distinction between its problem-solving and decision-making elements.

Barriers to the Problem-Solving Aspects of Rational Decision Making

Part II noted that patients require sufficient information to make full, informed choices. At a minimum, this requires clarification of: (1) the available alternatives; (2) potential outcomes for each alternative; (3) the costs, risks, and benefits of each alternative; and (4) the values attached by patients to each potential outcome. As noted, the required information has strong problem-solving components. Expert advice usually would be needed to structure the problem (ascertain the relevant choice and chance nodes of the decision tree) and to compute the probabilities of each event.

Clearly, patients are less likely than health care providers to have such knowledge. At the same time, people have been found to use a series of psychological rules of thumb (*heuristics*) which in turn may impede rational decision making (Eraker and Politser 1982; Hershey and Baron 1987;

Hogarth 1987). These heuristics are particularly likely to interfere with the ability to estimate and use probabilities.

For example, research indicated that people often make substantial errors in judging probabilities and making predictions (Nisbett and Ross 1980; Tversky and Kahneman 1981). Psychologists have catalogued several types of systematic errors to which both health care providers and patients are susceptible. Some of these (e.g., *representativeness* or *adjustment and anchoring*) result from individuals' difficulty in handling conditional probabilities. People are likely to ignore prior probabilities unless these are brought directly to their attention. They also may be influenced by the visibility of certain outcomes — the *availability* heuristic, which notes that individuals judge easily remembered things to be more probable than they actually are. Thus, well-publicized events (e.g., the birth of IVF babies) may be judged more probable than data would justify.

The approach to patient participation recommended in Part II implies that patients need considerable assistance in obtaining clear, accurate information. The psychological heuristics, however, imply that individual health care providers may not always be the best source of such information, since their judgments will be coloured by their own experiences. A particularly dramatic case is likely to influence probability estimates and, hence, to skew the resulting information. Thus, there appears to be a strong case for assisting individual health care practitioners and patients by encouraging the development of accurate information and mechanisms to pool available knowledge, verify its accuracy with clinicians, verify its clarity with a diverse group of patients, and make it readily available.

Measuring Preferences for Decision Making

Experts *cannot* determine what value will or should be placed on a particular outcome. Probabilities are factual; however, utilities are not. The degree to which it is or may be unpleasant to live with chest pain, to limit one's activities, or to be childless is inherently a personal value judgment. Accordingly, as noted in Part II, determination of the values to attach to outcomes requires patient involvement. As noted below, many heuristics also apply to the decision-making aspects of choice, particularly to measuring patient preferences.

Before describing the difficulties, however, it is important to present the normative standard; that is, how, in an ideal world, we would measure preferences. The usual approach is known as utility theory. Utilities are not only used in decision analysis — which attempts to help an *individual* make an optimal choice — but are also crucial to the related methodology of *cost-utility analysis*, which performs an economic analysis useful in making societal decisions.

It should be noted that use of such techniques restricts the researcher's attention to consequences that may be quantified and traded off. Whitbeck (1991) argued that many morally important consequences —

such as loss of integrity — lack that characteristic; thus, these techniques may lead to the neglect of important moral issues. Nonetheless, these approaches are becoming important ingredients of health policy decision making.

Measuring Utility in Theory and Practice

The Theory of Utility Measurement

Utility measurement is a technical (and often confusing) subfield in which jargon abounds and words take on different meanings than in everyday English usage. A noteworthy distinction is the difference between *valuation* (or *evaluation*) of an outcome and its measured *utility*. Only utility meets the theoretical requirements of decision-analytic or economic models. To oversimplify, utility includes a risk component, but valuation does not.

Currently, the accepted utility measurement is based on the von Neumann-Morgenstern utility index, which measures utility under risk. For example, assume that one wishes to determine how much \$10 is worth to an individual. Money has a designated value that is the same to everyone (\$10); however, it might not have the same utility to all in terms of ability to purchase goods or services.

Economists designate numerous ways in which the psychological importance of money might vary. One issue would be how much money one had already. Certainly, \$10 should be more important to a pauper than to a millionaire — a phenomenon referred to as the *declining marginal utility* of money. Another issue might be the timing of receipt. Most people would prefer to receive \$10 today than to receive it five years from now. Economic analysis must, therefore, deal with the appropriate *discount rate* to apply to deflate future costs or benefits.

Another source of valuation — and that addressed by utility estimation — is the riskiness of a situation. In terms of the previous example, individuals might attach different values to a guarantee of \$10 than to a gamble that, in the long run and if repeated an infinite number of times, could work out to the same expected value (e.g., a 10 percent chance of winning \$100, or a one-in-100 000 chance of winning \$1 million).

The classical *standard gamble* method of measuring utility focusses on such differing attitudes toward risk; it quantifies the value attached by an individual to a prize by using hypothetical lotteries. The first step in performing a standard gamble might be to offer an individual a choice between a sure payoff of \$10 and a *reference gamble* with an x-percent probability of the best outcome (say, \$100) and a (1-x)-percent probability of the worst (usually \$0). By systematically altering the value of x until the individual is indifferent in terms of preference between the two options, the utility attached by that individual to \$10 may be gauged. Thus, an individual's *risk attitude* — whether he or she is risk-averse or risk-seeking

— may be determined. A risk-neutral individual has a straight-line utility function.

Empirically, most people are found to have *inflected* utility functions; that is, they are risk-seeking in some areas and risk-averse in others. The extent of risk behaviour can be seen through the deviations from neutrality (in the previous example, where “a buck is a buck,” regardless of risk). Thus, the standard gamble is termed a risky or risk-based measure of utility, because it confounds an individual’s valuation of a particular outcome and the risk he or she is willing to accept to attain that outcome.

Applied to health care, decision theory measures utility for a given health state in an analogous fashion. The standard gamble measures an individual’s willingness to gamble with death (that is, utility under risk). For example, the value of a life on dialysis could be measured by offering the individual a choice between dialysis and a hypothetical intervention with an x -percent probability of cure (the best outcome, assigned a utility of 1), and a $(1-x)$ -percent probability of immediate death (the worst outcome, assigned a utility of 0). The probability of cure that would make that individual indifferent to the choice between dialysis and the gamble would be seen as the utility attached to the health state of life on dialysis, measured on a scale of zero to one. In theory, this technique may be used to construct a utility function that assigns numerical values to all possible combinations of number of life years to be spent in each possible health state (Mehrez and Gafni 1991).

Once the utility has been assigned, it may be used to adjust health outcomes. Suppose that one possible health outcome would provide an additional 12 years of life, with two years of perfect health followed by 10 years on dialysis. Suppose that the alternative (say, a successful transplant) would offer, on average, six months of poor health while recovering from the surgery, followed by an expected 10 years of perfect health. A utility of 1 is assigned to perfect health, 0.7 to life on dialysis, and 0.3 to the post-operative health state. By multiplying the utility of each health state by the number of years one would expect to spend in it, the number of quality-adjusted life years (QALYs) may be computed. Thus, dialysis would offer 12 years, but only $(2 + 0.7 \cdot 10)$ or 9 QALYs. Surgery would offer 10.5 years, but $(0.3 \cdot 0.5 + 1.0 \cdot 10)$ or 10.15 QALYs. The quality adjustment tips the preferred choice from dialysis to surgery. These computations underlie such economic approaches as cost-utility analysis, which compares the expected gains from alternative courses of action as a guide to policy makers. Clearly, such approaches are only as good as their utility estimations.

The Case Against the Standard Gamble

It should be noted that the standard gamble is, in theory, an attractive measurement technique. Like the decision theory of which it is a component, it can be described by a series of axioms that create a theory of impeccable logic. As noted, it is the underpinning for many economic

evaluations (e.g., cost-utility analysis) that attempt to influence policy. Why, then, has it come under increasing attack?

First, attempts to test utility theory have demonstrated that it provides a poor description of how people make decisions (Ben Zion and Gafni 1983; Llewellyn-Thomas et al. 1982; McNeil et al. 1978; Mehrez and Gafni 1987; Lopes 1981, 1987). While this fact is not decisive — it may be argued that utility theory describes how people should make decisions — it is a cause for unease. As the collapse of Communist regimes has demonstrated, theories of optimal human behaviour bearing little resemblance to human activity may have limited practical value.

Second, from a logistical viewpoint, the standard gamble has proved difficult to explain to subjects (Froberg and Kane 1989b). Patients may have difficulty understanding and remembering the necessary information (Mulley 1989), and clinicians may be unwilling or unable to spend the time needed. Again, in theory, these objections may be overcome with clearer communication. Efforts are under way to design visual tools and educational materials to help clarify the issues.

Third, from an empirical viewpoint, it must be recognized that the theory was devised to handle gambles in which a monetary prize could be gained. There is little evidence that it applies or was meant to apply to gambles in which a loss might be incurred. (Few ethics committees would approve an experiment in which the subject must pay the experimenter, although such research could easily be self-financing!) Neither is there good evidence about real (rather than hypothetical) gambles in which the benefits are non-monetary; in the health care field, however, one is confronted with possibilities of large non-monetary losses (e.g., death) (Deber and Goel 1990).

As Hellinger (1989) has shown, the relative distortion of responses increases as the probability of death increases; that is, people generally become more risk-averse as the probability of death in a gamble increases. That study concluded that individuals varied considerably in their risk attitudes, and that "risk attitudes are not absolute, but are functions of the parameters in the gamble" (Hellinger 1989, 279). Despite the theory's axiomatic attractions, it must be recognized that its applications to health care are extrapolations, which may or may not be justified.

Psychological Heuristics

From a psychological viewpoint, there also are numerous heuristics that may interfere with an individual's ability to estimate utility.

As an example, what is termed the *certainty effect* has been found to bias expressed patient preferences if gains and losses are involved (Brett 1981; Eraker and Politser 1982). This term refers to the finding that people will give great weight to outcomes that are certain as opposed to those that are merely probable (Tversky and Kahneman 1981). In medicine, an individual may, therefore, prefer the guarantee of a moderately good outcome over a gamble between either a very good or very poor outcome.

For such risk-averse patients, the utility of being certain to live for x years is greater than the utility of probably living for longer than x years.

Contrary to the utility-theory assumption that patients have a risk attitude that is constant and measurable, attitudes toward risk have been found to differ as a function of context. Thus, different determinations may be made in different therapeutic situations. This will depend upon the structure of the risks (Becker and Sarin 1987; Keeney and Winkler 1985; Lopes 1981, 1987; Sarin 1985), whether the decision is a one-time event or repeated (Lopes 1981; Deber and Goel 1990), and how the information is presented. A leukaemia patient, for example, may prefer a drug that certainly will extend life for a few more years over a drug that might extend life longer but may not work at all.

While some heuristics may be rationalized as logical (e.g., if a person is extremely risk-averse), others cannot. Among the most striking is what Tversky and Kahneman (1981) have termed *framing effects*. In an experiment, they asked 158 people to imagine a disease that would be expected to kill 600 if no action were taken. They offered two policy options: a "sure thing" and a "risky alternative." Option A would save 200 people. Option B would give a one-third probability of saving all 600 people, but a two-thirds probability that no one would be saved. Seventy-six percent of subjects selected option A. They next asked the subjects to select between two new programs. Option C would mean that 400 people would die. Option D would give a one-third probability that no one would die and a two-thirds probability that all 600 people would die. Although options A and C are mathematically equivalent, only 13 percent chose option C.

From most viewpoints, the framing effect is irrational, because it involves treating the same options differently depending upon how the choice is worded. Nonetheless, the framing effect has been shown to operate widely; unless choices are made explicit, people tend to be risk-averse in dealing with potential losses, although they may be risk-seeking in dealing with gains. Theorists are wrestling with efforts to devise new theories to accommodate the Tversky-Kahneman results. For example, Kahneman and Tversky (1979) have developed an alternative to SEUT, which they call prospect theory and which is currently being tested and modified by cognitive psychologists.

Inconsistent patient preferences often are due in part to limitations in cognitive processes (Eraker and Politser 1982; Froberg and Kane 1989a, 1989b, 1989c, 1989d; Herman 1985; Mazur and Hickam 1990; Merz and Fischhoff 1990; McNeil et al. 1982; Sutherland et al. 1983). As noted, framing effects suggest that patients' preferences may depend on the way information is presented. In one study (McNeil et al. 1982), surgery was considered more attractive for the treatment of lung cancer when the risk of operative mortality was described in terms of chances of living rather than chances of dying. Ambulatory patients with chronic illness, graduate students, and physicians were asked to imagine they had lung cancer and

to choose between radiation therapy and surgery, based on the cumulative probabilities and life-expectancy data. The treatment was identified or not identified to the subjects, and the outcomes were framed in terms of probability of living or dying. The subjects chose surgery more often over radiation therapy when the treatment was identified, when the information was presented in terms of life expectancy, and when the outcomes were framed in terms of probability of living.

Mazur and Hickam (1990) studied how the amount of information provided influenced patients' preference when framing effects were controlled. Patients and physicians were presented with two alternative treatments for an unidentified medical problem (whose data also derived from the previous example of lung-cancer treatment). Surgery offered better prospects of long-term survival but a risk of immediate death; radiation therapy offered better short-term survival prospects but worse long-term outcomes. All respondents were given data that included the probabilities of living and dying. When summary data were presented for three discrete times, patients preferred the short-term survival option; however, most respondents preferred the long-term survival option when more detailed information was presented (for six discrete times). Therefore, the investigators concluded that once framing effects were controlled, the amount of data presented also might affect patients' preferences.

Alder et al. (1991) suggested that these heuristics operate for IVF clients because abstract probabilities often are hard to understand and evaluate. They summarized evidence that the availability heuristic may distort perceptions (Johnston et al. 1987). In the case of IVF, these biases seem to increase estimates of success; women read newspaper stories about test-tube babies, and clinics post photos of successful candidates with their babies. No comparable attention is given to women who fail to conceive, and individual women are unlikely to have personal experience (e.g., friends who have tried IVF) to form their own estimates of success.

These heuristics can lead to systematic errors in estimating the likelihood of success. For example, although the live birth rate for IVF generally is lower than 15 percent, Stewart and Glazer (1986) reported that almost all couples beginning IVF expected to achieve a successful pregnancy. Similar overestimates of success have been noted in other studies (Callan and Hennessey 1988; Daniels 1989; Holmes and Tymstra 1987; Reading and Kerin 1989; de Zoeten et al. 1987). Although no studies have been carried out, Alder et al. (1991) suggested that framing biases also may apply; that is, women may respond differently to being told about a 15-20 percent success rate than they would to an 80-85 percent failure rate (*ibid.*, 114).

Unrealistic expectations of success might lead to over-use of treatment (e.g., continuing treatment for multiple cycles) and to heightened disappointment after failure.

In the case of diagnostic screening, however, the availability heuristic tends to lead to an overestimation of risk. Alder et al. (1991) found that

women referred for amniocentesis on the basis of age were likely to have friends who had undergone the procedure; in this case, the dramatic, memorable events that helped form their probability estimates tended to be complications (e.g., the need for multiple taps, or a miscarriage). Similarly, discussion was framed in terms of risks — a 1 percent risk of complications could seem greater than a 99 percent chance of no complications. As a result, women could feel unnecessary apprehension and even decline a potentially useful technology (ibid., 120).

Faden et al. (1987) also found a clear illustration of the certainty effect when examining prenatal diagnosis. Forty-six of 200 pregnant women surveyed said that they would have an abortion if there was a 100 percent chance that the fetus had a neural tube defect, but not if there was a 95 percent probability.

Conceptual Problems with Utility Theory

It may be argued that there are conceptual problems with utility measurement as now formulated. Indeed, the underlying validity of utility theory has come under increasing challenge (Lopes 1981, 1987; Schoemaker 1982). These problems may present particular problems in evaluating NRTs. Such conceptual problems include multiple dimensions to health, changing preferences depending upon current health state, and changing preferences over time.

Many conceptual dilemmas arise because health status, unlike monetary status, is a multivariate construct. Certainly, restrictions on physical activity may be valued differently by an active athlete than by a sedentary professor. But if this genuine difference in the valuation of an outcome is confounded with other factors, it may be difficult to interpret the results. It is always possible to expand the utility function and take account of more and more variables; this will compound the problem of interpreting the resulting utility.

As Gafni and Torrance (1984) noted in their critique, the standard gamble confounds the individual's view of a particular health state with numerous other factors, many of which parallel the issues confronting those trying to compute a utility for money. For example, utility is defined to take account of an individual's risk attitude. But the utility may also reflect an individual's attitude toward additional quantities of goods — and there may be a declining marginal utility for health, much as there is for money. People in a particular health state may rate factors differently from those not experiencing that state. Indeed, it has been observed that patients who have experience with a particular health status tend to give it different (and usually higher) ratings than those who have not experienced it (Sackett and Torrance 1978).

As an example, Boyd et al. (1990) examined the results of using different methods to measure the utility assigned to colostomy, a treatment for rectal cancer. They described the health state of an individual with a colostomy and asked five groups for their preferences using the standard

gamble, category scaling, and selection of their preferred treatment. Three of the groups had prior knowledge of this health state: (1) a group of surgeons and oncologists experienced with this disease; (2) a group of rectal-cancer patients who had undergone colostomy; and (3) a group of rectal-cancer patients who had received radiotherapy without colostomy. Two other groups of healthy subjects (older and younger individuals) had no special knowledge of rectal cancer. In general, patients who had had a colostomy and physicians consistently assigned higher utilities to the state than did patients without colostomy or healthy subjects. It must be noted, however, that those patients treated by radiotherapy may have refused surgery because they did not wish to live with colostomy.

This finding complicates the ability of policy makers to make determinations for health states based on public determinations of their merit. For example, the U.S. state of Oregon used a process of public consultation to decide which procedures were "worth" doing. But if the utilities given by the public do not match those given by people who must live with those conditions, whose preferences should prevail? What is a fair NRT policy if the fertile public would rank infertility treatment differently than would couples wishing such treatment, and if those ratings would likely change were they to enter that particular health state? Clearly, the public attaches a lower priority to such techniques as IVF than do infertile women. Whose preferences should count?

This finding also challenges individual decision making, since patients often must make decisions prospectively. It further supports the previous conclusion that it will be necessary to provide good information prospectively, possibly incorporating vicarious experience through self-help groups, filmed interviews, and similar mechanisms (Lyon et al. 1989).

Another major health policy dilemma is that a utility measurement also must take account of the individual's time-preference pattern, usually referred to as the *discount rate* (or *time value*). Just as one would rather receive \$10 today as opposed to \$10 in five years, so, by extension, one probably would prefer immediate health benefits to those that might be received in future. If so, by how much should such future benefits be discounted? And, if a discounted future benefit must be paid for in current dollars, would prevention programs be desirable? Might it be more "cost-effective" to invest prevention-program funds and allow the health problems to develop (particularly since not everyone at risk would fall ill, and some might die from other causes)? One could then use the accumulated investment to treat disease as it develops.

Thus, the logic of discounting suggests that programs with long-term payoffs (e.g., keeping young people from smoking, or preventing infections that might cause future infertility) have less value than those with short-term benefits (Weinstein 1986). Paradoxically, such arguments would encourage use of NRTs — which are directed toward those who both have fertility problems and desire children — and give lower weight to preventive programs directed toward the future reproductive health of all women

(some of whom might never encounter problems or wish to bear children), particularly because all benefits would occur at a future — and therefore discounted — date. If such arguments appear unpalatable, one must guard against uncritical adoption of the underlying premises.

Technical Problems with Constructing a Utility Function

Technical problems exist with constructing a mathematically satisfying utility function. For example, individual patients attach more weight to the next few years than to distant future years (Brock and Wartman 1990); however, these time preferences do not obey the rules of constant rate discounting and consequently work less well with existing models. Individuals are not neutral to gambles involving years of life (Hellinger 1989).

Contrary to theoretical expectations, utility measurement also is sensitive to the *anchor points* used. Conventionally, death has been used as the worst possible outcome (with a utility of 0); however, some people may believe that there are “fates worse than death.” Llewellyn-Thomas et al. (1982) showed that individuals rated health states differently when such fates (e.g., persistent vegetative state) are used as the anchor rather than death. But which anchor is correct? Clearly, such measurement instability casts doubt on the applicability of the standard gamble.

A more generic finding relates to the applicability of the anchoring-and-adjustment heuristic to measurement. Anchoring means that, whenever a quantity is judged, a natural starting point is used as an initial approximation. This anchor is then adjusted to accommodate the implications of additional information. Just as results from the standard gamble proved sensitive to the anchors used when the options were presented, Sutherland et al. (1983) showed that preference on category scaling (i.e., values assigned to health states as measured by linear-analog rating scales) was also contingent upon the type of anchor used. Compared to using the anchors “perfect health” and “death,” systematically higher values were assigned to the same states when the anchor of death was replaced by another health state, and systematically lower values were assigned when the anchor of perfect health was replaced.

Expanding the Utility Function

Experimental evidence has demonstrated that EUT is often inadequate as a descriptive theory (Eraker and Politser 1982; Hershey and Baron 1987; Schoemaker 1982; and Weinstein 1986). However, certain deviations from rationality can be accommodated by MEU theory if the utility function includes additional variables. In addition to the many dimensions to be considered in any non-monetary decision, numerous candidates for other dimensions have been suggested. For example, how should regret for “roads not taken” be handled (Bell 1982, 1985; Feinstein 1985; Hershey and Baron 1987; Loomes and Sugden 1982)? Or altruism, or preference for

an equitable distribution of social benefits? From a technical viewpoint, such factors may be accommodated by adding terms to the utility function.

At a certain stage, however, this approach resembles the efforts of ancient astronomers to preserve an earth-centred cosmology by adding endless epicycles to their orbits. Which additional factors should be added to the utility function, and is what remains interpretable?

Alternatives to the Standard Gamble

Numerous alternatives to the standard gamble have been proposed. Those in the first group retain a risk component. Although they may (or may not) be simpler to use, they remain subject to many of the same criticisms as the standard gamble.

Perhaps the best known of these alternatives is the *time trade-off*. This measurement approach again assigns a value to a health status by asking the individual to select between two hypothetical futures until an "indifference point" is reached. This time, however, the lottery trades time rather than probability of death; i.e., an individual would be asked whether she would prefer 10 years in health state A or nine years in perfect health, and the number of years in perfect health would be manipulated until her indifference point was reached (Furlong et al. 1990). In practice, this approach also may encounter difficulties. For example, Fowler et al. found that patients were upset by the method's presumption that they had only a limited number of years to live. The healthy year equivalent (HYE) is a new risk-based approach that allows for varying preferences over time, but requires derivation of an individual's full utility function (Mehrez and Gafni 1991).

There also exists a considerable developing literature on health-status measurement under risk-free conditions. Most of these measurements use what is termed a *category-scaling* approach (Fowler et al. 1988; Froberg and Kane 1989a, 1989b, 1989c, 1989d; Guyatt et al. 1986; Read et al. 1984), in which individuals are asked to rate their health states on a linear scale. The scale may be the familiar five-point Likert scale (i.e., some variant of "strongly oppose," "oppose," "neutral," "favour," and "strongly favour"). It may have an odd number of categories (i.e., it has a neutral point) or an even number. The scale may have three points, or seven, range from 0 to 100, or even allow for an infinite number of values (e.g., the variant that asks the individual to mark a point on a line, then measures the length of the line). It may use words, or pictures of faces that smile or frown (the Delighted to Terrible scale of Andrews and Withey 1976). They may measure subjective evaluations of the health state (Quality of Well-Being) or construct objective measures of how well individuals perform particular tasks (Activities of Daily Living). These scales may be single items (usually referred to as *holistic* measures) or elaborate scales (sometimes referred to as *decomposed* measures). Some have been well validated, others not.

There is extensive literature on such health-status measurements, and they are receiving increasing attention. In many ways, they resemble a subfield known as multi-attribute utility theory (MAUT), which seeks to construct a utility function assigning appropriate weights to a set of independent attributes (see Baron 1988, 312-17). These techniques are not measured under risk, however, and hence do not meet the formal axiomatic requirements of decision theory. Accordingly, purists have not viewed them as appropriate outcome measures for economic evaluations or decision analysis. For purposes of this paper, such measures will be referred to as "risk free," "category scaling," or "evaluations" of health states.

Comparing Risky and Risk-Free Measures

Risky and risk-free measures often give different answers. In general, if people are risk-averse, they will assign higher values to health states. Standard gambles are most susceptible to this bias (Wolfson et al. 1982; Read et al. 1984). The order in which techniques are used (e.g., category rating followed by standard gamble) also may interact with the style in which the scenarios are written (point form versus narrative form), producing different estimated utilities (Llewellyn-Thomas et al. 1982).

The theoretical disadvantages of a risk-based utility approach can be seen clearly in a study by O'Connor et al. (1987). This study elegantly shows the differences between patients' evaluations of health states and the utilities they assign to those states. Patients who had cancer were asked to evaluate two hypothetical drug therapies for cancer involving trade-offs between quality and quantity of life. One hypothetical therapy offered sure side-effects from treatment, while the other offered an uncertain probability. Patients' preferences were elicited before and six weeks following initiation of chemotherapy. The authors used the standard gamble (a risky method) and a riskless category-scaling rating method to elicit preferences.

They found that patients' preferences were unrelated to the way information about side-effects was presented; however, the riskless rating technique produced markedly different preferences from those elicited by the risky rating method. The preferences remained stable during treatment even though patients experienced side-effects following chemotherapy. O'Connor found that cancer patients rated "life on chemotherapy" as very unpleasant, but were unwilling to trade survival to avoid it. In such cases, the utilities for all states other than death would be compressed near 1, and differences between the values attached to different health states would shrink. Although the treatment choice would be unaffected by such a linear transformation, the computed utilities could give a misleading impression. Patients did not indicate that they viewed life on chemotherapy as nearly as good as normal life, but merely that it was the best of a poor set of options.

Further, the evaluation information intuitively appeared more useful to both patients and health care providers than the utilities; treatments evaluated as near 1 could be considered as giving good quality and those

with lower values as needing improvement. In practice, situations in which none of the options seems desirable may lead patients to seek new alternatives, such as unconventional therapies. In that sense, the utilities would not allow situations in which decision makers are satisfied with available alternatives to be distinguished from those in which they desire to add branches to the decision tree. Moreover, to the non-expert in decision analysis (which includes most physicians and patients), the utility or expected value of an outcome appears to be the same as its desirability.

Thus, although more mathematical variables may be added into the utility measure (Bell 1982), this makes interpreting the results more difficult. Life on dialysis may be acceptable to a sedentary professor who can read while using the machine, but it may be intolerable to an active athlete. Conceptually, the utility attached by each individual to a given outcome should capture this genuine difference in its value.

It has been argued (Deber and Goel 1990) that a multi-attribute health-status measurement best approximates the way most people conceptualize the value of a health state; indeed, patients often are reported to have difficulty working with utilities (Froberg and Kane 1989d; Mulley 1989). If two individuals rate a particular health status equivalently but differ in their risk attitude, utility measurements would imply that the more risk-averse individual places a higher value on that health status than does the individual more willing to gamble to achieve perfect health. This terminology seems to confuse rather than clarify. An alternative formulation seems simpler: two individuals assign the same value to the outcome, but use different rules to choose among alternatives.

This distinction has practical implications. The methodology underlying QALYs leads to the conclusion that the only symptoms worth alleviating are those so bad that a decision maker would rather die than put up with them (Goel and Deber 1989; Goel et al., 1989). It further leads to such intuitively unappealing conclusions as assuming that risk-averse patients must find life on chemotherapy less unpleasant than they say they do, since they are unwilling to run much risk of death to escape the side-effects. As a result, the von Neumann-Morgenstern utility index appears to be comparatively insensitive to differences in quality of life and comparatively sensitive to differences in life expectancy. Accordingly, the existing risk-based methods of measuring patient values (standard gamble) tend to understate the impact of interventions that improve quality of life. The resulting systematic bias in the value attributed to health states affecting primarily quality of life can affect cost-utility calculations on the individual or societal level, often favouring curative over preventive or rehabilitative interventions.

The policy implications of this bias are particularly important in analyzing NRTs, because women unwilling to risk death to bear a child still may value parenthood highly. It has been suggested that use of the *decision-rule* approach could separate the value placed on an outcome from

the risks one is willing to run, thus permitting wider use of health-status measurement approaches (Deber and Goel 1990).

Decision Making and Decision Rules

Decision theory has assumed that the normative theory of rational choice requires selecting the branch that maximizes the expected value of the outcome; however, Deber and Goel (1990) have noted that other normative rules may be appropriate under certain circumstances. The decision-rule approach requires the decision maker to specify which rule will be used to choose among options. Decision rules are categorized by whether they consider: (1) aspects of outcome distributions beyond central tendencies; (2) probabilities as well as utilities of outcomes; and (3) means as well as ends. The distribution-based decision rules could address both individual risk and justice for a population. Rational choice under risk if choices are one-time-only, rather than repeated events, or if one branch contains unlikely but disastrous outcomes, might ignore probability information. Alternative rules (e.g., minimize maximum loss, maximize maximum gain) may be particularly appropriate when outcomes are non-monetary and/or when gambles risk losses (rather than gains). Incorporating the risk attitude into the decision rules, rather than into the utilities, could facilitate use of multi-attribute approaches to measuring outcomes.

It is possible that the decision-rule formulation would permit a more parsimonious treatment of risk preference than traditional treatments, which attempt to incorporate many dimensions into utility functions. It is known that the estimates of the value of an outcome elicited by linear-analog scales differ from those arising from standard gamble or time trade-off, and that different lottery techniques may give different utility measures (Fischer 1977; Hershey et al. 1982; Hershey and Schoemaker 1985; Llewellyn-Thomas et al. 1982, 1984; Llewellyn-Thomas and Sutherland 1987; O'Connor et al. 1987; Read et al. 1984; Torrance 1976a, 1976b; Torrance et al. 1982). Category scaling approaches measure preferences for health states, whereas utilities measure a combination of preferences and risk attitude (Krzysztofowicz 1983). The decision rule approach would then replace utility by the value placed on a health state. It would allow explicit specification of how an outcome would be measured, and place the independent judgment of how much risk an individual is willing to take to attain it within the specified context, into the decision rule.

What Preferences to Measure?

Two basic data sources have been examined to determine what outcomes are considered important for NRTs. The first source consists of various opinion surveys that study the attitudes of clinicians, candidates for different NRTs, and/or the public. (The relevance of these sets of

preferences depends upon one's view of who should be making the decisions.) The second source is less "scientific" but in many senses far richer: women's accounts of experiences with the technologies. From this, a list of possible outcomes important to some women may be extrapolated.

These surveys tend to look at only some of the issues surrounding use of NRTs. Although they are not its focus, this paper notes some studies about attitudes toward IVF, donation in general, and prenatal diagnosis as classified by target groups (the public, health care providers, and families using NRTs).

Attitudes Toward Reproductive Technologies

In general, the public appears to approve of the use of IVF. A survey was conducted in Australia to measure attitudes of the public toward the use of IVF and embryo transfer to help married couples have children (Kovacs et al. 1985). It found general support, particularly among those under age 35 and those with higher education. There were lower levels of approval for embryo freezing (45 percent approved, 33 percent disapproved, and 16 percent were undecided) and use of donor gametes (56 percent approved, 23 percent disapproved, 21 percent were undecided) than for IVF.

The same survey indicated that there was no consensus about the use of surrogacy. Of the 66 percent who had heard of it, 25 percent approved, 31 percent disapproved, and 10 percent had no opinion (Kovacs et al. 1985). Birke et al. (1990) cited a study by LeRoy Walters, Director of the Center for Bioethics, Georgetown University, which concluded, "Throughout the world, public opinion polls have found less than one third of their samples to have favourable attitudes to surrogacy, and all seven of the major governmental reports oppose it" (cited in Birke et al. 1990, 264).

A majority of obstetricians and gynaecologists surveyed in New Zealand approved of the use of IVF (Daniels 1987); however, many specialists in these fields believed that legislation and guidelines were needed to reduce the possibility of abuse.

Holmes and Tymstra (1987) surveyed mothers of IVF babies, women who had had one or more unsuccessful IVF attempts, women on the IVF waiting list, and fertile women with two or more children. A majority of women, particularly the infertile women, indicated that they had always wanted children, that to have a child was a fundamental right, and that health insurance should pay for IVF.

Nonetheless, IVF may be associated with considerable stress for the women undertaking it. Holmes and Tymstra (1987) noted that women who had undergone IVF procedures reported experiencing most stress while waiting to learn whether an embryo would implant. Mao and Wood (1984) surveyed women who discontinued treatment, finding that psychosocial distress and cost were the most common reasons for discontinuing treatment. In contrast, all women who had a baby using the procedure were satisfied with the treatment and would recommend IVF to other infertile women.

Mao and Wood (1984) measured attitudes; they did not investigate whether these factors actually predicted whether women would continue in an IVF program. Callan et al. (1988) surveyed 254 women who had completed at least one attempt of an IVF cycle to see whether psychological variables, social pressures, and sociodemographic characteristics could predict reported intentions to continue or discontinue the treatment.

In general, women's background characteristics did not predict as well as social pressures or attitudes. Women who discontinued the treatment tended to have more children, older husbands, had been on the waiting list for less time, and had more IVF pregnancies. The discontinuers were less optimistic about another attempt, and they did not feel that another attempt would improve the quality of their lives. These women reported fewer social pressures and they did not think their husbands or doctors felt they should undergo another IVF attempt; however, the factors in Callan et al.'s model explained only about half of the variance in women's reported decisions about continuing IVF.

Frank (1989) surveyed 147 infertile couples' preferences about treatment options and the factors they perceived as most important in making their treatment decisions. Medical regimens, DI by husband, and surgical procedures were the preferred treatments. As noted in Part IV, it may be argued that these categories of NRTs present the fewest policy dilemmas. The most important factors influencing couples' decisions about infertility treatment were personal beliefs, partner's beliefs, physician's advice, and emotional stress. These findings reaffirmed the high stress experienced by most infertility-treatment patients and suggest that distress can influence decisions.

The attitudes of New Zealand families toward secrecy and DI were explored in studies of 37 donors in six DI programs, and 55 couples who had been accepted into one of the six DI programs. Both groups thought secrecy was important, but both the couples (once conception had occurred) and the donors had told their immediate family and close friends. Forty-one percent of donors and those wishing to become parents via DI did not feel that children should be told of the nature of their conception; however, 46 percent of couples had not yet decided whether they would tell their child. Donors were almost equally divided regarding the child's right to non-identifying donor information. Thirty-eight percent of donors believed that children who knew they were conceived via DI would want information about the donor, whereas only 12 percent of recipient couples believed children would want the information. Only 19 percent of donors and 5 percent of recipient couples believed that a child would want to know the donor's identity, yet 75 percent of all respondents stated that the issue is far from clear-cut. The author recommended greater recognition of the child's needs and rights, commenting that the issue of secrecy tended to serve those empowered to make decisions, to the detriment of the child's

rights (Daniels 1988). It seems likely that secrecy in DI will come under similar pressure for disclosure as has occurred for adoption.

The attitudes of 234 infertile couples undergoing IVF were examined concerning gamete donation (Oskarsson et al. 1991). A high proportion of couples deemed giving sperm samples for donation acceptable for therapeutic, diagnostic, and research purposes (77 percent, 90 percent, and 97 percent, respectively). Attitudes toward egg donation were similar to those toward sperm donation: 72 percent of couples would donate eggs to another woman, 84 percent would donate for diagnostic purposes, and almost 90 percent would donate eggs for research. Of the 160 couples willing to donate eggs, 41 percent said they would do so even under non-anonymous conditions. Only 12 percent were interested in meeting the recipients, and 4 percent wanted to choose the recipient. More than two-thirds (69 percent) favoured providing non-identifying donor information to the recipient couple. In contrast, 40 percent favoured giving similar information to the child. Like Daniels (1988), the authors concluded that a significant proportion of couples who felt unsure about how to deal with some of these emotional, ethical, and legal considerations would like focussed counselling.

Similarly, Birke et al. (1990) cited a study by Alder et al. (1986) on attitudes of women attending ante-natal and family-planning clinics in Edinburgh toward IVF and embryo research. More than 70 percent thought women should be allowed to donate eggs for research, and more than 60 percent said they might be willing to donate eggs (Birke et al. 1990, 100).

With respect to prenatal diagnosis and screening, there is relatively little information on women's attitudes and opinions. As noted by Birke et al. (1990, 179),

Unfortunately, little time or money has been spent trying to find out what women think... Few studies tell us about the attitudes and experience of women in screening. Most ask in general terms whether patients were happy with the service they received. Such surveys tell us little, as many studies have shown that people in such situations tend to express satisfaction with whatever form of health care they receive.

Variables that have been found to be important to women's decisions about amniocentesis versus chorionic villus sampling (CVS) for prenatal diagnosis have been summarized by Alder et al. (1991) (See also Lippman et al. 1985) Key variables included timing of the procedure, time to results, risk of miscarriage, and termination method, each of which was important to at least 75 percent of the sample.

However, Alder et al. (1991) summarized evidence that women vary considerably in their evaluation of the benefits and risks related to using prenatal diagnosis in the first place (*ibid.*, 119-20). Faden et al. (1987) suggested that white, middle-class, pregnant women are more likely to view as justifiable the abortion of fetuses with cognitive rather than physical

disabilities, although these views may not apply across all ethnic and class groups (Faden 1991).

In a survey of some 70 women in Leeds, reported in *The Lancet*, 70 percent of women surveyed regarded a Down syndrome birth as worse than a miscarriage after amniocentesis, but this ranged from women who would always refuse amniocentesis to those who would have it even if the risk of a Down syndrome baby were as low as 1 in 20 000. The authors concluded that amniocentesis was being underused, particularly for women under age 35, based on women's own values (*The Lancet*, 26 July 1986, 225, cited in Birke et al. 1990, 180). They cited Bernadette Modell of University College, London (from a BBC Horizon program on the ethics of clinical trials, November 1987), who noted that, before a randomized clinical trial (RCT) of amniocentesis and CVS, women in two settings were told the pros and cons of each test and asked to choose one. In London, everyone wanted CVS, while in Oxford, everyone wanted amniocentesis (Birke et al. 1990, 181). This result provided evidence for two common-sense conclusions: choice is highly influenced by the way information is presented, and not all women have the same preferences.

Another inference as to the variation in women's attitudes comes from studies on the use of amniocentesis in Ontario. Before 1975, less than 2 percent of women over age 35 had amniocentesis; after that date, use increased every year, reaching a little more than 50 percent in 1985. Studies estimated, however, that although 70 percent of women in the relevant catchment area had contact with the centralized clinic in 1983-85, almost 20 percent either refused counselling or declined the procedure after counselling (Hunter et al. 1987).

Experiences

A valuable volume with an inflammatory title is a collection of papers edited by Klein (1989). The book, *Infertility: Women Speak Out About Their Experiences of Reproductive Medicine*, is subtitled "Reproductive Technology Fails Women: It's a Con." From these feminist accounts, outcomes considered important by women may be extrapolated. Klein stressed the following adverse aspects:

1. the small likelihood that women who try IVF will have a baby (current success rates are 5-10 percent);
2. health hazards for women, including:
 - (a) effects because "the technology is invasive";
 - (b) effects on the reproductive system from hormones administered to induce superovulation, including risks of ovarian cysts, septicaemia, and adhesions;
 - (c) effects on women from "hormonal cocktails," including migraine headaches, dizziness, vision problems, weight gain, depression,

and other long-term possible but unknown hazards such as breast cancer and ovarian cancer;

- (d) effects from diagnostic work-ups (ultrasound, contrast media, etc.) including pain, bleeding, and long-term impact;
- 3. health hazards for children born from IVF, quoting the past experience with diethylstilbesterol (DES);
- 4. psychological effects on women due to the following:
 - (a) discovery of a fertility problem, including guilt, anxiety, loss of self-esteem, severe depression, and the need to keep trying;
 - (b) worry about future health (related to the cause of the infertility, hormonal problems, and residual effects of therapy), including hopefulness/hopelessness and loss of control over their own fertility;
- 5. ethical problems from using drugs or techniques in women, which are of unproven benefit and unknown safety;
- 6. ethical and feminist concerns about: exploitation of women and attempts to control their fertility, particularly in developing countries; genetic engineering (these writers urge women to resist medicalization of reproduction via NRTs because it will affect all women's control over their lives); and priorities (e.g., spending money on NRTs when many women do not get prenatal care);
- 7. "Painful journeys" through infertility treatment, with lives placed in limbo, including such issues as interference with sexual relationships, loss of spontaneity, and temperature record-keeping that serves as a constant reminder of infertility;
- 8. reinforcement of women's feelings of a need for children at any price, and its relationship to:
 - (a) sense of identity and importance;
 - (b) powerlessness of women;
 - (c) stigma attached to childlessness and shame from infertility, including pressure from society and from one's spouse;
- 9. violation of women's dignity;
- 10. difficulty in quitting once they have started;
- 11. risk of multiple births; and
- 12. impact on the relationship (sexual and marriage), especially if the spouse wishes to "carry on his name."

At the least, it seems important that information should be available concerning each potential problem. Decision analysis could then help to determine which of these factors could "tip" the optimal choice, and which

utilities must be clarified. It is likely, for example, that many of the above factors often would be irrelevant (either because there was no increased risk, or because decisions would not vary over any feasible range of values attached to that variable).

Nonetheless, it must be recognized that the mere posing of questions about preferences and outcomes adopts an individualistic model and assumes that these are individual-choice issues. Critics of NRTs often argue that this is a flawed, incomplete way of addressing the issues. First, it must be recognized that decisions take place in context. Second, externalities exist, and decisions may affect more than just the decision maker. Concerned parties must be identified, and may be seen as including only the woman (as some argue for the decision not to bear a child), and/or the child, the partner, those paying the bills (insurer), and society as a whole.

Part IV: Whose Values and Wishes Should Determine Policy?

In Parts II and III, an individualistic model of decision making was implicitly assumed. An autonomous decision maker, presented with clear information about the available options, would weigh it and make her choice. But choices cannot be separated from the context within which they are made. Part IV discusses caveats to the individualistic model, suggesting that its applicability will vary depending upon the NRT in question. A typology of NRTs is proposed that may shed light upon policy decisions.

Is Shared Decision Making Possible?

This paper strongly argues for the ideal of shared decision making. Barriers to shared decision making may arise, however, if patient and health care practitioner are seen as inherent adversaries. This belief appears as an undertone in many feminist attacks on NRTs.

The Klein volume, for example, is characterized by a distrust of both physicians and research, and a sense that research is being done for the benefit of the physicians rather than that of present or future patients, particularly given the potentially lucrative returns from NRTs and biotechnologies in general. Klein drew parallels to eugenics and Nazi-era medicine, while others (e.g., Winkler and Schoenenberg 1989) considered the technology "a new degree of violence against women." They added, "it appears that the onus to find solutions for social and eco-political problems has been transferred to (involuntarily childless) women who are thus forced into performing their social role — which is to bear children at any price." From this viewpoint, shared decision making would be a myth, since

inherently exploitative behaviour should be eradicated as unethical. Other feminists, however, maintain an ethos of individual choice and consider this line of writing an "insult" to infertile women. Clearly, the language of individual decision making makes strong policy assumptions.

Individual Choice and Women's Rights

Feminism has fought for reproductive rights under the slogan "freedom to choose." It has argued strongly that individual self-determination requires that women be able to control their own bodies (McNeil et al. 1990). This individualistic approach is strongly rights-based, which implies that even unwise decisions must be respected. For example, a 1965 U.S. court decision (*Griswold v. Connecticut*) held that married couples had a right to privacy that was infringed by state prohibitions on contraceptive use. Similar privacy arguments were later used to extend the right of individuals to decide whether to have an abortion (Areen 1989, 102). Similar pro-choice arguments have been made by feminists in Canada, the United Kingdom, and elsewhere.

In effect, this ideology would assume that the choice of whether to use NRTs should be made only by the individuals concerned, unless strong evidence is introduced to the contrary.

Feminists also have been ambivalent about use of the language of rights. As McNeil et al. (1990) noted, "the language of rights is, after all, the language of bourgeois liberalism. As such, it can reinforce rather than transform the established social order ... It begs the questions of who has the right to such choices, thereby ignoring how race, class and sexual orientation influence the possibility of choice" (ibid., 10).

A second objection to the language of rights is that "the language of individual choice also infuses the language of consumerism," which can mean that reproduction can become increasingly commodified (McNeil et al. 1990, 10). Feminists adopting this viewpoint are faced with making an uneasy distinction between choice and freedom (ibid.). Although containing an element of truth, this formulation bears a strong resemblance to the Marxist opposition to "false consciousness," and can be patronizing and "insulting to infertile women" (Birke et al. 1990, 318, n.5). These U.K. feminists wrote:

Given the difficulty of changing individual desires, there have to be strong arguments about the social undesirability of a practice if it is not to be employed to try to satisfy such desires... Having fought for fertile women to be able to decide these important matters for themselves, we should not then hold a much more patronising attitude to infertile women and see them as incapable of making choices. (Birke et al. 1990, 19)

The Context of Choices

All choices are made within a context. "All reproductive decisions can be taken only within the context of society, which means that the decision

either way is heavily influenced by economic pressures, the expectations put on women, and the alternatives society leaves open to them" (Birke et al. 1990, 13).

Petchesky argued that reproductive freedom is both social and individual, operating "at the core of social life as well as within and upon women's individual bodies" (Petchesky 1984, 2).

Rothman (1987) questioned whether the concept of "freedom of choice" applies to situations in which all alternatives are unpleasant. Her study of women facing the decision whether to abort or bear a handicapped fetus noted that these women did not perceive themselves as having choice; they often talked about the decision made as their "only choice" (ibid., 180). The emphasis such women would put is on the lack, not the availability, of choice that the combination of their social and medical conditions imposes on them.

Most reproductive choices are similarly constrained. The choice to terminate a pregnancy may be discussed, but a woman may feel pressured to make this decision because of insufficient resources (financial or social) to be able to raise a child, because society devalues the disabled, or because of preference for a son or daughter. Most feminists nonetheless support abortion rights in these circumstances, although with some discomfort.

Perhaps because of the intensity of the women's struggle to avoid being defined purely by biology, some feminists have greater difficulty dealing with women choosing to attempt to bear children through use of NRTs. They argue that choice and informed consent cannot exist as long as motherhood is considered the normal path for women, or as long as a patriarchal society devalues women and their work. Sandelowski (1986, 446-47) wrote, "Women are not free *not* to choose cures for infertility given the price they pay for not trying hard enough to become mothers ... Women's demand for and satisfaction with medical treatments for infertility, which often inflict more physical and emotional pain than they relieve, may represent the most devastating kind of subversion of individual choice." Similarly, Crowe concluded that "'choice' is always mediated by social circumstances. In a situation where women experience personal condemnation and social stigma because of their infertility, and in which the social definition of motherhood necessitates a biological relationship, the question must be asked what *real* 'choices' do infertile women have?" (Crowe 1987, 93). She argued that the IVF procedure "reflects a male-centered view of parenthood in that it centers on conception and the production of a biological child" (ibid., 88).

Such remarks should be considered helpful in reminding individuals that autonomous choice alone may be insufficient to assure an optimal outcome, but it probably remains a necessary factor. Ideally, women would not feel pressured to make certain choices; however, that they do is not an argument for designating others to make available choices for them. Similarly, an argument that adoption should be equally acceptable to

parents wishing a child is unhelpful if there are few children available for adoption.

Who Should Make the Decision?

The argument that decision making is inherently constrained by a patriarchal society thus may lead to a devaluation of women as potential decision makers. The argument may be that women do not have enough information to make appropriate choices. For example, Soloman (1989, 185) wrote, "Infertile women are powerless against their doctors — if they 'misbehave' they are out of the program/clinic. They are uninformed, or misinformed, and are thus unable to make real choices." However, this argument has an easy policy solution: ensure that women have the information they need. Soloman continued, "I believe that in this social climate women still have very little choice, but the information must be made available ... Someone has to be there to tell the doctors what infertile women really want and how we feel; to explain to women what the full procedures are likely to be, what the risks are, and what the possible outcomes might be" (ibid.). Presumably this view would agree that, once the woman is informed, her choice should be respected.

Others, however, believe that societal pressures mean women no longer have the ability to choose. These writers stress that "apparent choices" should not be treated as real. For example, Hubbard (1982) argued that the availability of new choices all too rapidly becomes a compulsion to select the "socially endorsed alternative." This argument is cited by several authors, especially Pappert (1989). These arguments are sometimes characterized by a failure to distinguish between the decision-making and problem-solving dimensions of choice. For example, Steinberg (1990, 113) argued that "choice for women in this context is at best a derivative, consumerist choice" because "women can consent to preexisting options which they have had no substantive role in determining." But, as argued in this paper, if information is accurate, complete, and understandable, determination of options in no way determines selection.

Thus, ideological debate rages about who should be the decision maker. At one end of the debate are feminists who argue that, because women are most affected by pregnancy and are responsible for caring for and rearing a child, only women should decide about contraception, abortion, and childbearing (e.g., Birke et al. 1990). Steinberg (1990) objected to including the spouse as a decision maker because the woman undergoes the procedure. Birke et al. (1990) favoured NRTs on the feminist ground that it is advisable to encourage the separation of social parenting and biological processes. Such writers believe that if the stigma attached to placing children for adoption is reduced, the decision to raise children could be viewed as a conscious commitment to a child's well-being.

Next, some theorists assume that choice belongs to the couple. The definition of "couple" varies — from stable, middle-class, married

heterosexuals of “acceptable” moral character to lesbians or single women with appropriate support networks. There is considerable dispute as to what role should be played by the male partner. (Many authors assume only the male is concerned with obtaining a genetically related child.)

Another potential decision maker is the child. Some critics believe that an embryo should have full human rights from conception; others believe that an embryo is only a potential human until it is born. Deciding that the potential child should have a voice introduces other problems. For example, should a child be able to sue its parents for negligence if, for example, the mother engaged in potentially harmful behaviour, such as working in a hazardous environment or using alcohol or drugs during pregnancy? If so, must a guardian be appointed to make decisions on behalf of the unborn child? Similar issues arise when considering whether women should be compelled to submit to prenatal genetic testing. Some public health programs do routine prenatal screening for neural tube defects or neo-natal screening for phenylketonuria and sickle-cell anaemia, for which consent is not obtained (Faden 1991). But Faden stressed that “it seems reasonable to expect that in most cases pregnant women are supportive of anything that can be done to improve prospects for their babies” (*ibid.*, 45). Other writers similarly decry the emphasis on such admittedly unusual situations, noting that under current technology an embryo cannot develop without its mother’s active involvement, and the mother virtually always wants only the best for her potential offspring (Birke et al. 1990).

The appropriateness of allowing the physician to decide who has access to NRTs also is under dispute. Health care practitioners seem to define the treatment, set the standards of eligibility for treatment, and determine the particulars of individual treatment regimens (Steinberg 1990, 113). Writers disagree about whether doctors — or independent counsellors — should be able to determine who can receive treatment on the basis of who would make good parents. Viewpoints depend in part upon whether the dominating metaphor is natural birth (unscreened and private) or adoption (for which the state takes a major role in attempting to protect the child’s best interests).

Finally, it must be asked whether society should be able to make these decisions. Almost immediately, issues of equity arise. For example, to what extent should NRTs be reserved for stable, middle-class, married couples? What access should single persons, lesbians, minorities, and poor and/or disabled women have to these technologies? And should a distinction be drawn between access to technologies and the requirement (particularly salient in a system of national health insurance) that the state pay for these procedures? This judgment also will be affected by the metaphors chosen: if treatment for infertility is medically necessary, presumably it should be covered by health insurance; if it is a private, elective procedure, presumably it should not.

Other questions also arise. For example, if genetic testing reveals that a fetus will be disabled, or even that it has risk factors for later disease, one may ask whether a society concerned with rising health care costs should have the right to demand that the pregnancy be terminated (Rodin and Collins 1991, 4). Should such demands be linked with ability to pay; that is, should the medical costs of such children be publicly or privately financed?

The choice of decision maker is important for two reasons: first, as noted in Part III, the way in which a question is framed may help determine how it will be resolved. Decision making about NRTs often involves balancing several desirable but mutually exclusive values. In the United Kingdom, the Warnock report on NRTs noted that “society may value things, genuinely and quite properly, which are incompatible with each other” (quoted in McNeil et al. 1990, 192). McNeil interpreted Warnock’s attempted compromise as having reformulated utilitarianism and figured in the social harm of offending others’ moral sentiments. This is analogous to efforts to add variables to the utility function, as discussed in Part III. Anticipating the inevitable attacks from conservatives for its basic acceptance of “artificial” methods of reproduction, Warnock adopted an even-handed tone and a balancing-interests approach. McNeil’s critique noted that the report’s framing of the issue embedded fundamental assumptions about morality and family that undercut feminist beliefs concerning reproductive decisions, the position of women, and alternative households.

In its very title, *A Question of Life*, the Warnock report framed the central moral issue as to whether or how human beings ought to “bring life into the world” or “destroy life.” Other ways of framing “the moral issues” — for example, the distribution of responsibility for children after birth, the distribution of power over reproductive decisions, the conditions of informed consent, or women’s health needs — are nowhere considered (McNeil et al. 1990, 192).

Even once an issue is framed, there are diverse values and preferences concerning reproduction. Different decision makers are likely to reach different decisions. For example, what is parenthood? Some put high value upon a biological (genetic) connection between parents and child; others find it trivial and unimportant (e.g., Klein 1989; Franklin 1990; Birke et al. 1990). Some claim that this linkage is particularly important to men (Overall 1987) and that women tend to feel more comfortable with adoption. Others argue that parents appreciate the similarities between themselves and the child. “A parent can also enjoy witnessing her own parents’ talents or personality emerging in her children. There is a sense of continuity and history created by the genetic tie” (ibid., 154). “The assumption... seems to be that the genetic link with a child is paramount, equalling or even surpassing the value of what has been called ‘social parenthood’... What is important is not merely to have a child but to have a child who is one’s own” (ibid., 151). In contrast, Michael D. Bayles

argued that only cultural conditioning makes people believe that rearing their own genetic offspring is preferable. "Many people have raised children in the erroneous belief that the children were their genetic offspring when they were not, so the only difference seems to be the belief" (cited in *ibid.*, 153). The question of the validity of desiring genetic links is a strong theme in some writings by European feminists, among whom the class elements in adoption do not loom as large as in North America.

How important is it that a child be "perfect," fitting parental wishes concerning physical features, absence of disabilities, and perhaps even gender?

How important is it for a woman to bear a child? To many feminists, it is a waste of female potential to put a life on hold while trying to become pregnant. Self-actualization should be found in other directions.

How just is it to devote resources to aiding infertile women when many children worldwide lack the necessities for a good life?

Not all NRTs evoke all of these issues. It may be suggested that different NRTs are likely to imply a different balance among the various interests involved; use of a single umbrella term does not help to clarify the extent to which individual preferences should dictate policy.

The categorization of NRTs provided in this paper, although derived independently, bears some resemblance to that of Haimes (1990), who distinguished three components of a "normal" family: (1) the ideological element, which dictates a link among marriage, sex, and reproduction; (2) the structural element, according to which the ideal family comprises two parents plus children; and (3) the genetic element, which dictates that the child should be the genetic product of both parents.

Haimes related approval of NRTs to the extent to which they threaten this family definition. She argued that scientists tend "to classify the application of the technology into three forms" (Haimes 1990, 163). Concerning Haimes' first category of NRTs, there is "no moral objection to its practice" (Warnock 1985, 18) because users are simply correcting nature's errors. This category includes DI using the husband's sperm and IVF without egg donation. It was argued that, because these technologies satisfy the components of a normal family, most may see them as unproblematic. The second category — using donors — threatens only the third component; if secrecy is maintained, they can maintain the ideological component and mimic the structural component. A third category — technically possible but seen as socially undesirable — violates these norms. Single parenthood, for example, violates both the ideological and structural components; surrogacy undermines the birth experience and may be seen as subverting motherhood. "The surrogate's role is too immediate, too long in terms of time and too threatening to the concept of motherhood" (Haimes 1990, 166).

Categorization of New Reproductive Technologies

As proposed in this paper, the first category of NRTs, including microsurgery, strongly resembles standard medical treatments. Like those other treatments, they evoke questions of whether the benefit outweighs the risk or justifies the cost. Technology assessment, cost-effectiveness analysis, and decision analysis provide tools for studying this category of procedures. It may be decided that a procedure is not worth doing, that it is worth doing only if an individual will pay for it, or that it is so valuable that society should provide it. Issues concerning who should have access will arise, as they will for other forms of therapy. The analysis is more complex for this category of NRTs than for other medical treatments only because risk and benefit must be evaluated for both mother and potential offspring. As Haimes observed, however, this category of procedures does not challenge societal values; treatment choices may be analyzed considering primarily values placed by individuals upon particular outcomes.

Each of the NRTs considered evokes such risk and cost-benefit questions; however, the other categories of NRTs described in this paper also raise further issues.

The second category of NRTs, including IVF and DI by partner, adds the question of separating reproduction from sex. The major ethical objection raised against this category is that it separates lovemaking and procreation (Walters 1989) and, as such, is opposed by the Roman Catholic Church (Birke et al. 1990, 44). This objection is based on the ideal of reproduction and the rejection of technology to assist the process. Those who promote DI by partner and IVF argue that nature's failure has caused the separation of reproduction from lovemaking. Further, infertile couples who resort to these technologies do so to extend their sphere of affection to include the physician's office and the assistance of technological intervention. In general, most societies tolerate this category of technology, considering it a personal concern and of interest to the individuals involved only.

The third category of NRTs includes DI and surrogacy. Here, not only is reproduction separated from lovemaking, but biological parenthood is separated from social parenthood. This approach also was mentioned by John A. Robertson who viewed surrogate motherhood as "one type of 'collaborative reproduction' — that is, reproduction in which a third person provides a genetic or gestational factor not present in ordinary paired reproduction" (cited in Overall 1987, 113). This category lies between adoption and standard reproduction (with or without assistance), because there is a genetic link between at least one of the social parents and the baby. To maintain the appearance of a normal family, however, secrecy has been common. Until laws were clarified, DI could be classified as adultery. Its opponents argued that the practice undermines the family and may have a negative psychological impact on the husband or the potential child

(despite evidence that there is no psychological harm to the husband if consent is obtained [Walters 1989]). DI probably will evoke similar pressures for disclosure of "biological parenthood" as has adoption. In turn, this will challenge parents' efforts to mimic the structural family unit. Indeed, Sweden passed a 1985 law giving children the right to know the donor's name, which led to a decrease in the number of people seeking DI in Sweden. Birke et al. (1990) suggested that this decrease may have been due in large part to people seeking DI in other jurisdictions not subject to that law.

DI presents numerous ethical dilemmas. It has been argued that it is paramount that children be reasonably informed of the circumstances of their conception (Walters 1989). Efforts also must be made to ensure the safety of donated semen (to avoid disease transmission) although efforts to screen for genetic history have been challenged by some as discriminatory to the handicapped. Walters suggested that the minimum standard should include history of the donor's family and the screening for infectious diseases. Permanent, confidential records should be maintained about the donor's health status, and follow-up sessions with the donor may be required.

Given the recent history of adopted children, it is likely that if DI children learn their origins, they will want to be able to identify their genetic fathers. It is now a relatively accepted practice to tell adopted children as soon as possible that they are adopted. Concerning DI, however, the consensus appears to be not to tell because no one is ever likely to learn the truth; to the world, the pregnancy appeared to proceed normally (Daniels 1988). Again, it can be predicted that this practice will face increasing challenge.

Another objection raised about DI is the commercialization of the reproductive process when donors are paid or when a surrogate mother rents her womb by use of DI. Critics have argued, for instance, that the collection of sperm should be done in a voluntary, non-profit way. France has handled the commercialization of reproduction by setting up a centralized system for semen donors.

The fourth category of NRTs, which includes prenatal diagnosis, evokes questions concerning abortion and the sanctity of life. Clearly, there are varying views on the appropriateness of aborting an affected fetus or using embryonic tissue for research.

This category of NRTs is noteworthy for enabling at-risk couples to have healthy offspring and thus preserve the genetic link between parents and offspring. For instance, Overall (1987) noted that couples who carry genetic diseases prefer to use prenatal diagnosis and abortion rather than DI. "The real value of technologies of artificial reproduction is that they enable infertile individuals to have their own children in this genetic sense, and this tends to be regarded as the only valid treatment of the desire for a child" (*ibid.*, 150).

The use of prenatal diagnosis now makes it possible to detect an increasing number of genetic defects. If prenatal testing shows that the fetus is abnormal, then selective abortion may be carried out, thereby decreasing the propagation of genetic defects (Spallone 1989). Many argue that these technologies are morally justifiable if they help a couple avoid transmitting a serious genetic disorder to their children, but not for more trivial purposes (Walters 1989). The issue then becomes who will define which characteristics are undesirable.

The use of prenatal screening to detect the sex of the fetus when no X-linked medical disorder is likely, that is for purely social reasons, raises ethical concerns about promoting sex discrimination. Others have said that aborting a fetus for a genetic defect gives a negative message about the perceived worth of the disabled (Rodin and Collins 1991). If prenatal diagnosis were ever to be available and operate within a market system, could there be a class bias in disability (since only those with money would be able to access the technologies that can reduce such births)? In turn, will society be as willing to assist those born disabled by "choice" (either because a mother did not choose abortion, or because she was unable to obtain information)? Spallone argued the importance of "the social, economic, and political commitments which are necessary to support the parents of disabled children, and the social supports necessary to enable the disabled" (Spallone 1989, 121).

An ideology of choice — inherent in support of abortion rights — may lead to results that society finds unpalatable. For example, repeated studies confirm that both men and women prefer sons. The accumulated evidence indicates that in some societies: (1) generally, sons are preferred over daughters to a greater extent by men than by women; (2) a boy is strongly preferred as the first child; (3) if there is to be only one child, a boy is preferred; (4) if an odd number of children are desired, most parents would rather have more boys than girls; and (5) parents may be more likely to stop bearing children after producing a son than after producing a daughter (Overall 1987, 29).

Should it be acceptable to use prenatal diagnosis to enable the selective abortion of female fetuses? Overall advocated re-educating individuals' beliefs about and attitudes toward women to offset the strong preference for males; however, this may be insufficient.

The fifth category of NRTs — gene therapy — also raises questions about the long-term integrity of the gene pool. Walters promoted gene therapy only if future generations will be freed from passing on genetic defects. This preventive strategy will reduce the chance of couples transmitting genetic problems to their descendants. The benefits would not only be for the couples and their descendants, but also for society at large.

This category evokes strong ethical dilemmas. Among the most potent is the question of whether human beings are sufficiently wise to "play God" and redesign the gene pool. Additional issues involve whether gene therapy will inevitably lead to eugenics by coercing people to participate in the

program, or whether a gene-therapy program will lead to the attempt to create perfect human beings for a perfect society. Finally, different cultures will have different ideals of what a human being is, making consensus virtually impossible (Walters 1989). The power to decide, in this context, would be enormous. Most people feel reluctant to allow individuals this power, but they are equally reluctant to vest it in the state. To date, it has been dealt with by science fiction and, it would seem, by a fervent desire that the issue just go away.

Policy Implications

This paper suggests that individual preferences will be most salient for the first two categories. This implies the likely usefulness of technical aids — decision analysis and technology assessment — that may assist patients and health care providers in selecting effective and desirable medical treatments.

Conclusion

In summary, this review of the literature makes the following suggestions:

1. decision making should be conceptualized as a shared process between patient and clinician;
2. patients wish to be informed;
3. patients probably wish to participate in decision making about their care, but not in doing the problem-solving tasks;
4. most patients will need expert assistance to do the problem solving (identifying and structuring information) necessary for decision making;
5. the necessary information includes not only medical factors, but also a wide range of social and psychological effects;
6. this information may not be readily available; consensus-building efforts to determine, prepare, and disseminate such material should be helpful;
7. existing methods of measuring outcomes are unlikely to be sufficiently sensitive to the quality-of-life concerns important to NRT-related decisions; thus, cost-utility analyses may be premature;
8. individual preferences will be most salient for those NRTs falling into the first two categories proposed in this paper; models for selecting medical treatments based on their effectiveness and their fit with patient wishes (e.g., decision analysis and technology assessment) should prove useful; and

9. individual preferences, although important, are not the only factors for those NRTs falling into categories 3, 4, and 5, since societal views and values must be included in making policy decisions about these issues, and such decisions may, or may not, involve the determination that such decisions should be left to the individual.

Appendix 1: Glossary of Terms

AID: Artificial insemination by donor (now called donor insemination [DI] to avoid confusion with acquired immunodeficiency syndrome [AIDS]).

adoption: To become a legal parent of a child.

anchor: A measurement term for the best (and worst) possible outcomes, which define the highest (and lowest) values that could be assigned. For health measurements, the conventional anchors are death (with a value of 0) and perfect health (with a value of 1).

anchoring and adjustment: A psychological heuristic. Whenever one judges quantity, one selects a natural starting point as an initial approximation. This anchor is adjusted to accommodate the implications of additional information.

artificial insemination: (AI) See *donor insemination*.

assisted reproduction: See *reproductive technology*.

autonomy: In ethics, the principle that an individual's independent actions and choices should not be constrained by others even if they seem unreasonable or irrational. Also referred to as respect for persons. Autonomy underlies informed decision making. See *informed consent*.

availability: A psychological heuristic. People judge those things they can remember easily to be more probable than is the case.

beneficence: Mercy, kindness, or charity. In ethics, the principle that one must benefit others or help others further their legitimate interests. Beneficence may conflict with autonomy.

bioethics: See *ethics*.

biological parent: See *genetic parent*.

category scaling: A measurement technique used to assign values to health states, usually measured on an ordinal scale with clearly defined endpoints or anchors.

chance node: In decision analysis, a way of depicting an event in which multiple outcomes are possible, when these outcomes are beyond the decision maker's control.

certainty effect: A psychological heuristic. People will give greater weight to outcomes that are certain than to those that are highly probable.

choice: The act of selecting a course of action. Deber and Baumann subdivide choice into decision-making and problem-solving situations.

choice node: In decision analysis, a way of depicting an event in which multiple outcomes are possible when these outcomes are under the decision maker's control.

collegial model: A model of decision making, proposed by Veatch, in which patient and physician are equal partners in decisions.

conditional probability: Probability attached to an outcome, given that a related event already has happened (e.g., the probability that a surgical complication will occur, given that someone is in a particular age group).

confidentiality: A moral obligation founded on another's claim to privacy. This ethical principle is a fundamental component of the physician-patient relationship, stemming primarily from the Hippocratic oath; may conflict with other ethical principles (e.g., beneficence).

consumer: An individual who purchases an item of value.

contractual model: A model of shared decision making, proposed by Veatch, in which physician and patient work together.

cost-benefit analysis: A form of economic analysis in which costs and consequences are valued in equivalent (usually dollar) terms.

cost-effectiveness analysis: A form of economic analysis in which costs are valued in monetary (usually dollar) terms and consequences are valued in another metric (often, additional life expectancy, but also cases detected, babies born, etc.).

cost-utility analysis: A form of economic analysis in which costs are valued in monetary (usually dollar) terms and consequences are valued in quality-adjusted life years.

DES: See *diethylstilbestrol*.

decision analysis: A systematic approach to decision making under conditions of uncertainty; it requires the decision maker to structure the decision problem. Steps include specification of the available alternatives, identification of potential outcomes, estimation of the probability of each outcome, assessment of the utility assigned to each outcome, computation of the expected utility for each course of action, and selection of the "branch" offering the highest expected utility.

decision making: Process of choosing among alternatives; used by Deber and Baumann to refer to situations in which choices must take into account decision makers' values and preferences.

decision rule: The rule used to select among options after the decision problem has been structured. The most common decision rule is "maximize expected utility," but other possibilities (e.g., "minimax" or "maximin") also may be appropriate. The maximin rule computes the minimum payoff associated with each potential choice, then selects the branch with the highest minimum possible payoff. The maximax rule computes the maximum payoff associated with each branch and selects the branch with the highest maximum possible pay off.

decomposed measurement: An approach that enables the investigator to obtain values for all health states without requiring a judge to assign values to each one.

diethylstilbestrol (DES): A synthetic estrogen administered to pregnant women (mostly in the 1960s) to prevent miscarriage. Never proven effective in preventing miscarriage, DES has been found to cause cancer, genital-tract anomalies, and/or decreased fertility in some individuals exposed *in utero*.

discount rate: The rate used to deflate future costs (or benefits) in economic analysis.

donor gamete: Egg or sperm donated by individuals for medically assisted conception.

donor insemination: (DI) The introduction of sperm into a woman's vagina, cervix, uterus, or fallopian tubes upon ovulation by means other than sexual intercourse, for the purpose of conception. This also is referred to as assisted insemination or artificial insemination by husband (AIH) when the sperm comes from the male partner. Formerly, when the sperm was donated anonymously, it was referred to as AID (see *AID*).

economic analysis: The comparative analysis of alternative courses of action in terms of their costs and consequences. Examples of economic evaluation include cost-benefit, cost-effectiveness, and cost-utility analysis.

embryo: In humans, the term used to describe the organism during its growth stages, from about the second to the ninth week following conception. During this period, cell differentiation proceeds rapidly, and the brain, eyes, heart, upper and lower limbs, and other organs are formed. The stage from fertilization to the appearance of the embryonic axis (14 days after fertilization) is referred to as the pre-embryonic stage.

engineering model: A model of decision making, proposed by Veatch, in which the physician is a technician providing expert advice and the patient is the sole decision maker.

ethics: The study and articulation of moral principles and rules of conduct that may be used to evaluate the rightness or wrongness of human decision making and behaviour.

eugenics: The study of means to improve the hereditary qualities of a population by encouraging transmission of traits deemed desirable (positive eugenics) or discouraging those deemed undesirable (negative eugenics).

expected utility: See *utility*.

fertility: The ability to produce offspring; a woman's ability to conceive and carry a child or a man's ability to impregnate a woman and have a child born of the impregnation.

fertilization: Fusion of an oocyte (egg) and sperm, and subsequent combination of the two sets of chromosomes (23 each).

fetal therapy: A more general term than fetal surgery, it includes the established procedure of intrauterine exchange for Rh incompatibility and experimental procedures of drug or vitamin treatment of inborn metabolic errors.

fetus: The organism at the developmental stage marked by growth and specialization of organ function; in humans, usually considered to be from the ninth week of gestation until birth.

fidelity: An ethical principle referring to the obligation to keep promises and contracts.

GIFT: See *gamete intrafallopian transfer*.

gamble: In decision theory, the requirement to make a choice whose outcome cannot be known with certainty (i.e., to make decisions under risk or uncertainty).

gamete: The mature male or female reproductive cell, containing one set of chromosomes (the haploid number) rather than the two sets (the diploid number) found in somatic (body) cells. In men, the gametes are sperm; in females, eggs or ova.

gamete intrafallopian transfer (GIFT): A technique of medically assisted conception in which eggs are removed from the body, mixed with the partner's sperm in the laboratory, and immediately replaced into the woman's fallopian tubes so that fertilization occurs inside her body.

genetic parent: The individual whose sperm or egg produces the fertilized embryo; also referred to as *biological parent*, as contrasted with the *social parent* (responsible for nurturing and rearing the child).

health status: As defined by the World Health Organization, "health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity".

health-status measurement: The process of assigning a number to reflect an individual's judgment of the relative merit of living in a particular health state.

heuristics: Principles commonly employed to generate subjective probability estimates. (See *representativeness*, *availability*, *anchoring and adjustment*.) Subjective probabilities often are biased (i.e., inaccurate) when not assessed by direct reference to frequencies of observed event.

holistic measurement: An approach requiring a judge to assign scale values to each possible health state, when a health state represents a combination of many attributes.

in vitro fertilization: A technique of medically assisted conception most often used when a woman's fallopian tubes are blocked, diseased, or damaged. Mature oocytes (eggs) are removed from a woman's ovary, usually after administration of an ovulatory stimulant, and fertilized with sperm in the laboratory. After fertilization and incubation, the fertilized egg is placed in the woman's uterus (embryo replacement). (See also *GIFT*.)

in vivo fertilization: Conception within the female body, which can occur through intercourse or DI.

infertility: Inability to bring about conception and bear a child despite repeated attempts. The time required to warrant a diagnosis of infertility may vary, but usually is considered to be one to two years of intercourse without contraception. A distinction may be made between *primary infertility* (when a couple has never conceived) and *secondary infertility* (when a couple has conceived at least once, with conception resulting in miscarriage, abortion, or stillbirth). *Sterility* refers to the inability to conceive or to bring about conception.

informed choice: Choice based upon possession of sufficient information about a particular procedure and available alternatives.

informed consent: A legal, ethical principle dictating that an individual give his or her permission to receive treatment, particularly potentially risky treatment. Thus, informed consent requires information about risks and benefits. It is seen as a necessary, but not sufficient, condition for ensuring patient autonomy, since informed consent may not necessarily imply informed choice.

informed decision making: A term reflecting the desirability of progressing beyond the formalistic approval inherent in *informed consent* to a genuinely informed choice.

insemination: Placement of semen within the vagina or cervix.

justice: An ethical principle, generally referring to fairness. In ethics, the principle that one should act in such a manner that no one receives a disproportionate share of benefits or burdens. Theories of distributive justice are concerned with the proper division of benefits and burdens, based on the notion that individuals have rights that must be safeguarded.

Likert-style question: A question measured on an ordinal rating scale, usually ranging from "strongly agree" to "strongly disagree."

linear analog: A measurement scale in which intensity of preference is "mapped" onto a linear scale.

medical decision making: Decision making applied to medical questions.

MEU: The decision rule known as "maximize expected utility." See *utility*.

microsurgery: Delicate surgery performed with the aid of a microscope or other magnifying apparatus. In cases of infertility, it may be used to repair the fallopian tubes or the vas deferens.

multi-attribute health-status measurement: A measurement that begins by gauging dimensions (attributes) of a given health status, then combining them into a summary measure. (Compare to *holistic measurement*).

non-maleficence: A fundamental ethical principle associated with an obligation not to harm others.

normative: Desirable.

ovum donor: A woman who donates an ovum or ova to another woman.

participation, patient: The process by which a patient is involved in making decisions about his or her own care.

paternalism: An ethical principle — now generally rejected as applying to competent adults except under exceptional circumstances as a violation of autonomy — implying a responsibility to act on behalf of another for his or her own good.

patient: A recipient of medical treatment.

pre-embryo: See *embryo*.

preference: The level of satisfaction, distress, or desirability associated by an individual with a particular health state (see *value*).

prenatal diagnosis: Testing before birth to determine whether a fetus has a specific trait, usually a malformation or disease for which the fetus is

known to be at increased risk because of maternal age or a positive family history.

priestly model: A model of decision making, proposed by Veatch, in which the physician makes decisions on the patient's behalf.

probability: The likelihood that an event will occur, usually measured on a scale of 0 (impossible) to 1 (certain). Probability estimates may be subjective or may be derived from analysis of the frequency with which such events occurred in the past.

problem solving: Deber and Baumann use this term to refer to choice situations in which there is one correct answer (e.g., a mathematical exercise), which may require expert knowledge to ascertain. (Contrast with *decision making*.)

provider: A health professional providing health services; may be a physician, a nurse, a genetic counsellor, etc.

quality-adjusted life year (QALY): A measurement of health outcome sensitive to the differences in perceived quality of different health states. The QALY is derived by multiplying the additional life expectancy in each particular health state by its utility, then adding them. The QALY is a common outcome measurement for cost-utility analysis.

representativeness: A psychological heuristic. The probability assessment for an uncertain event is influenced by the degree to which the event is similar in essential properties to a larger class of events.

reproductive technology: Also called *new reproductive technologies* (NRTs). Biomedical or technical interventions in the process of procreation, including (but not restricted to) DI, IVF, embryo replacement or transfer, prenatal diagnosis for genetic defects or sex, embryo research, fetal tissue research, and fetal tissue transplantation.

risk: Situations whose outcome cannot be known. Decision making under risk refers to situations in which the probabilities of different outcomes are known; decision making under uncertainty refers to situations in which the probabilities are unknown. In common parlance, but *not* in decision theory, risk refers only to the probability of a hazardous event, such as the occurrence of a genetic defect.

satisfaction: Ware's results suggested that patient satisfaction should be divided into the "art of care" and the "technical aspects of care." Most patient-satisfaction surveys suggested that patients take the technical component for granted and focus upon the interpersonal factors in the doctor-patient relationship.

shared decision making: A process whereby the patient and health care provider make active, essential contributions. Providers bring training, knowledge, and expertise to the diagnosis and management of patients' conditions. Patients bring a knowledge of their own subjective aims and values, through which risks and benefits of treatment options may be evaluated.

standard gamble: The classical measurement of utility, this technique offers an individual a choice between the certainty of living in a particular

health state and a gamble between an x -percent chance of perfect health and a $(1-x)$ -percent chance of death. The probability of death is varied until the individual is indifferent between the two options.

sterility: See *infertility*.

surrogacy: The practice whereby a woman bears a child for another couple, with the intention of handing over the child after birth. Fertilized eggs may come from the *surrogate mother* or from the recipient couple (using *embryo transfer*).

surrogate mother: A woman who carries an embryo to term, with the intention of relinquishing the child at birth.

time trade-off: A risk-based method to obtain quasi-utility values for a health state; considered by some to be simpler to administer than the standard gamble. The time trade-off asks the respondent to choose between a fixed number of years in a particular health state and a lesser time in perfect health; the number of years in perfect health is varied until the respondent is indifferent between the alternatives.

truthfulness: An ethical principle obliging the health care provider not to lie to the patient; may be linked to obligations to disclose relevant information.

uncertainty: See *risk*.

utilitarianism: In ethics, a principle referring to the obligation to produce a net balance of benefits over harms.

utility: In decision theory, a measurement of the value (under risk) assigned to a particular health state. Utility usually is measured on a scale of 1 (the best outcome) to 0 (the worst outcome) and often is defined by the result of the *standard gamble*.

valuation: Also, *evaluation*. In measurement, the numerical value given to a health state, measured under riskless situations (often using category-scaling techniques).

value: In health-status measurement, the number assigned to a particular health state; more generally, refers to an individual's moral preferences for particular outcomes. The personal values of patients and the health care provider regarding possible outcomes come into play in reaching clinical decisions.

von Neumann-Morgenstern utility index: See *standard gamble*.

willingness to pay: Technique used in cost-benefit and cost-effectiveness analyses to quantify programs difficult to evaluate in monetary terms by asking what an individual would be willing to pay for a particular benefit.

Appendix 2: Research Approach

Procedure

This literature review employed the following procedure:

Books and articles were scanned for applicability to the subject. Those meeting this review's entry criteria were entered into a computer data base, using predefined templates for theory-based articles or data-based studies. All material was assigned keywords to enable the data base to be searched.

Additional material was identified (e.g., books or articles cited in the material already identified) and processed as described above. The final data base consisted of 378 entries (and 141 key words). The data base was searched, the material analyzed, and the report written.

Search Strategy

This review employed the following multifaceted approach:

A computer search was performed on the following data bases:

MEDLINE CD-ROM, 1985-1990

MEDLINE on diskette, 1966-1991

Social Sciences Index CD-ROM, updated to 1991

General Sciences Index CD-ROM, updated to 1991

Excerpta Medica CD-ROM, 1988-1991

Scandoc Data Base (University of Toronto Science and Medicine Library)

A separate search was conducted on MEDLINE to ensure that French and foreign-language material was included. Keywords used for these computer searches are indicated below.

A "backward" search of applicable references cited was performed among the articles chosen, and a "forward" search of the Science Citation Index was performed for articles citing the references chosen.

Journals likely to publish material on these topics also were scanned.

Keywords Used in Search

Reproductive Technology Keywords

Artificial insemination, heterologous

Artificial insemination, homologous

Assisted reproduction

Donor screening

Embryo transfer

Fertilization

Fertilization *in vitro*

Genetic engineering

Genetic screening

Infertility, female

Infertility, male

Infertility counselling
 Infertility treatments
 Reproduction techniques
 Reproductive health care
 Reproductive technology
 Semen donors
 Sex preselection
 Surrogate mothers
 Surrogacy

Decision-Making/Utility/Health-Status-Measurement Keywords

Attitudes to health
 Choice behaviour
 Consumer satisfaction
 Decision analysis
 Decision making
 Decision rules
 Empowerment
 Ethics
 Health outcomes
 Health priorities
 Health-status measurement
 Information seeking
 Informed consent
 Knowledge of results
 Measurement
 Patient attitudes
 Patient education
 Patient involvement
 Patient participation
 Patient preferences
 Patient values
 Problem solving
 Treatment decisions
 Utility
 Utility measurement

Combinations Searched

Each NRT keyword was searched in combination with (1) preferences, (2) attitudes, (3) values, (4) utility, and (5) decision making. This search also included the following keyword-phrases:

Decision making and ethics
 Measurement and health outcomes
 Measurement and utility
 Participation and decision
 Problem solving and decision making

Treatment decisions and involvement
Utility and decision making

Coding Scheme for Theoretical Articles

Abstract:

Intervention:

Reproductive technique? (Yes/No)

If yes, specify

Deals with (check all applicable):

Decision making?

Problem solving?

Participation?

Information seeking/requirements?

Preferences

(If yes):

Specify decisions/problems

Type of study:

Data-based

Theory

Ethics

Opinion

Comments on:

Problem-solving/decision-making distinction (explicit, implicit, n/a)

Decision rules

Utility/health-status measurement

Participation

Keywords

Coding Scheme for Data-Based Articles

Abstract:

Intervention:

Reproductive technique? (Yes/No)

If yes, specify

Deals with (check all applicable):

Decision making?

Problem solving?

Participation?

Information seeking/requirements?

Preferences

(If yes):

Specify decisions/problems

Type of study:

Data-based

Theory

Ethics

- Opinion
- Subjects:
 - Sample size
 - Gender
 - Age
 - Medical conditions
 - Location
 - Date
 - Marital status
 - Other characteristics
- Providers:
 - Type
 - Number
- Study design:
 - Survey, randomized trial, case control, other (specify)
- Measurement:
 - Outcome measure used
 - Questionnaire (Yes/No); if yes, specify details (number of items, source)
 - Scales used
 - Results
 - Validity/reliability information
 - Reliability/validity of questions
 - Eligibility criteria (selection bias?)
 - Strength of study design (confounding variables)
 - Completeness of follow-up
 - Method of handling withdrawals
 - If appropriate, include key measurement items:
- Comments on:
 - Problem-solving/decision-making distinction (explicit, implicit, n/a)
 - Decision rules
 - Utility/health-status measurement
 - Participation
- Keywords

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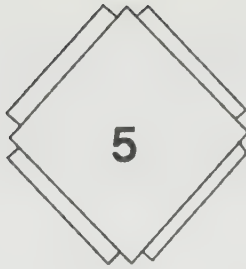
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The Psychosocial Impact of New Reproductive Technology

John Wright



Executive Summary

Infertility and treatment for infertility are reportedly associated with psychological stress and psychosocial deterioration. Previous research suggests that medical fertility treatment (MFT) intake, in itself, is associated with high levels of psychological distress. The present study examines the evolution of psychosocial adjustment of 686 fertility clinic patients over 24 months, and was a subset of a larger comprehensive study that is not yet complete.

The study incorporated questionnaire measures of a wide range of psychosocial dimensions. A measure of socially desirable responding was also administered because of the likelihood of the participants' set to create a good impression to help ensure their inclusion in the treatment program. Analyses of variance and correlation coefficients permitted comparisons of scores indicating psychiatric symptoms, socially desirable responding, psychological stress, marital satisfaction, sexual satisfaction, and self-esteem. Available social support was determined, as was the type of psychosocial support participants requested during treatment and their suggestions for the future.

MFT is associated with a high treatment abandonment rate, but little is known concerning the causes. Therefore, the research incorporated measures of treatment intrusiveness, and client satisfaction

and dissatisfaction. Clients' suggestions for improvement were systematically requested from the second to fifth time of testing. Telephone follow-ups by psychologists were conducted with a subsample of the patients who dropped out of treatment.

This report includes detailed results for each of the following five topics:

1. *Evolution of psychosocial adjustment in IVF patients:* There was evidence that *in vitro* fertilization (IVF) patients did experience a drop in sexual satisfaction over the 24 months they were followed, but there was no clear evidence that IVF patients who participated in the study reported increased problems in areas of mental health, self-esteem, or stress. We think the present study underestimated the actual amount of mental health problems because many couples terminated treatment without pregnancy and did not participate in the study after treatment cessation.
2. *Intrusiveness of IVF:* IVF was rated as being much more disruptive of various spheres of life by both men and women in areas such as morale, work, and recreation as compared to the other treatments.
3. *Satisfaction with IVF services:* The vast majority of men and women (>80%) from couples who received IVF reported high satisfaction with services offered by the medical and paramedical staff. However, one particular area of clinic functioning received consistently high dissatisfaction ratings (up to 41%) — the failure to provide adequate information on topics such as adoption, prognosis, and side-effects of treatment.
4. *Couples who abandoned medical treatment:* This study succeeded in contacting 138 couples who dropped out of treatment (IVF and other pooled together) before becoming pregnant. The following factors were rated as most important in motivating this decision: (1) too much psychological suffering; (2) lack of dialogue with treating physician; (3) inefficacy of treatment; (4) lack of moral support from the medical team; and (5) lack of information about diagnosis, treatment side-effects, and prognosis.
5. *Requests for psychosocial support services:* The strongest suggestions consistently underline the desire of patients to have more dialogue with their treating physician in order to increase the quality of decision making. The first priority of the patients is to be better informed. Requests for more moral support by the medical team, access to a nurse and/or psychologist at the outset of, or during treatment, and access to a support group were all rated above the mid-point on the seven-point scale, but were not scored as high as requests for more information on medical decision making. Increased availability of more psychological services at the outset of treatment was rated as a priority by 50% of women, and

increased availability of psychological services during the course of treatment was highly recommended by 35% of women.

A brief description of results offers insight into the complexities of infertility and its treatment, and suggests directions for future research. The author offers a number of concrete recommendations concerning the treatment process.

Authorship and Breadth of This Report

Although many researchers and clinicians contributed directly and indirectly to the research reported here, because of time constraints only one author, John Wright, was available to write the final report. Hence, all the opinions expressed in this document reflect the position of the present author. It is possible, even probable, that my co-researchers (Claude Duchesne, M.D., Stéphane Sabourin, Ph.D., and Andrée Chatel, M.Ps.) would have different opinions regarding the presentation of the data in some sections.

The five topics covered in this report submitted to the Royal Commission are from a larger ongoing study that will be finished and available for publication after September 1993. In the final version, (1) different statistical analyses will have been completed that will be more sensitive to overlap between dependent variables, (2) chronological data will be employed to better isolate the onset of any deterioration in psychosocial functioning and pregnancy status, and (3) a profile of high-risk patients will be presented.

Introduction

The Evolution of Psychosocial Adjustment in IVF Patients

Mental health professionals and the public have postulated that the inability to conceive can trigger a variety of psychosocial disturbances, such as depression, anxiety, marital discord, and sexual difficulties (Dunkel-Schetter and Lobel 1991). In addition, many clinical publications contend that existing medical diagnoses or treatments intended to overcome infertility trigger further deterioration of psychosocial functioning (Mahlstedt 1985; Menning 1980). To date, the vast majority of publications concerning the deleterious effects of medical fertility treatment (MFT) have relied on research designs with so many shortcomings (biased, small samples, retrospective instead of prospective designs, short time frame, failure to include male partners, unreliable or limited dependent measures, etc.) that conclusions are not at all on firm ground (Ellsworth and Shain 1985; Olive 1986; Wright et al. 1989).

When minimal scientific design quality is used as a selection criterion, there are, in the writer's opinion, 13 relevant studies of the psychosocial impact of fertility clinic diagnostic workup or treatment. Of two controlled

studies on psychosocial functioning before and after medical diagnosis, Takefman et al. (1990) concluded that psychosocial distress increased from pre- to post-diagnosis; however, Daniluk (1988) concluded that individual psychological problems appeared to be highest at the first interview and decreased during the course of diagnosis. No change in marital and sexual adjustment was observed for the majority of couples (ibid.).

The only two studies of surgery revealed contradictory results; however, time of testing might explain the difference. Lalos et al. (1985) found increased depression, grief, and sexual and marital problems 24 months after unsuccessful laparoscopy. Wallace (1985) found no difference in psychological adjustment in women who underwent tubal surgery to remove blockages (infertile) compared to women who had ligatures (sterilization). However, the former group was tested a few weeks after surgery, and thus could still hope for effective pregnancy.

Four studies report psychosocial data gathered after artificial insemination with donor sperm (AID) (Bendvold et al. 1989; Blaser et al. 1988; Levie 1967; Manuel et al. 1982), while three studies used pre- and post-treatment measures (David and Avidan 1976; Reading et al. 1982; Rosenkvist 1981). Taken as a group, the studies suggest that psychosocial distress levels drop for couples who successfully achieve pregnancy using AID. David and Avidan (1976) and Rosenkvist (1981) found that psychological and marital or sexual problems remained high in the unsuccessful group. Furthermore, many studies claimed to have scientifically documented psychosocial deterioration from before to after *in vitro* fertilization (IVF) treatment (e.g., Baram et al. 1988; Freeman et al. 1987; Leiblum et al. 1987; Mahlstedt et al. 1987; Newton et al. 1990).

Only the Newton et al. (1990) study included enough scientific controls to yield reliable conclusions: 213/947 women and 184/899 men were tested three months before and three weeks after a first trial of IVF. Data were not analyzed on the 26 (12.2%) women and 24 (13%) men who reported pregnancy in themselves or their partners. The authors found significant increases from before to after IVF treatment on measures of anxiety and depression in the unsuccessful group, particularly for women. The authors measured marital adjustment before IVF but unfortunately not afterward.

One final study (Berg and Wilson 1991), though retrospective in nature, sampled 104 couples at different phases of diverse fertility treatment programs. The authors found a significant drop in psychiatric symptoms from year one (mainly diagnosis cases) to year two, but a significant increase above initial levels for both male and female patients after three years of treatment. They found no significant change in marital or sexual satisfaction in year one to year two comparisons, but did find significant drops in marital satisfaction for women of the year three group, and lower sexual satisfaction in both male and female patients.

Because of the complexities revealed in data such as the above, the first purpose of the present study was to investigate the evolution of the psychosocial adjustment in patients who received IVF as compared to other MFT.

Treatment Intrusiveness

A factor that many clinicians claim is responsible for psychosocial deterioration of MFT patients in general, and recipients of IVF in particular, is the intrusive nature of the treatments (Klein and Rowland 1988; Menning 1980). This term, originally presented by Devins et al. (1983), refers to the extent that treatment regimes disrupt, interfere with, or constrain continued involvement in important areas of functioning. Although the notion of treatment intrusiveness has yet to be systematically explored with MFT, this dimension of stressful medical treatment has been investigated in several well-controlled investigations of end-stage renal disease (Devins et al. 1990). Several studies have demonstrated that renal patients' ratings of overall intrusiveness vary with the treatment modality received and are stable over time, and the degree of disruption of a given life sphere (leisure activities, physical health, couple relations) varies for the four most commonly used treatments for end-stage renal disease (Binik et al. 1990; Devins et al. 1990).

A second objective of the present study was to develop a measure of the intrusiveness of diverse MFTs and to assess fluctuation in perceived intrusiveness according to (a) MFT received, (b) the sex of the client, (c) life domain affected, and (d) duration of treatment.

Satisfaction with Services

Although many reports suggest that a significant number of fertility clinic patients are dissatisfied with certain aspects of their treatment experiences, the present author could find no controlled study of client satisfaction. Therefore, another objective of the present project was to study patient satisfaction.

Couples Who Abandoned Treatment

As with all psychosocial research on voluntary clinical populations, high subject attrition rates present a major challenge. Research concerning the treatment of fertility is particularly difficult, because patients terminate MFT at very high rates in spite of treating physicians' recommendations. Drop-out rates are among the highest of modern medical treatments. Undoubtedly, this finding can be explained partly by the absence of physical suffering associated with the condition of infertility, for the vast majority of patients. The objective of most couples is not to cure a symptomatic or painful condition, but to have a baby. Little systematic research has contrasted patients who persevere with those who abandon

treatment, and little is known about the motive behind MFT termination initiated unilaterally by the patient. A fourth objective of the present study was to investigate these questions.

Psychosocial Support Services Requested by Couples

During the last 15 years, many publications have recommended that mental health professionals offer a variety of services in fertility clinics: assessment, screening, support, counselling, crisis intervention, and long-term therapy. To date, most research on this question has simply reported what psychosocial support services patients requested, were open to, or retrospectively reported that they would have appreciated. Because previous studies have asked only isolated questions about the need for more psychosocial services, a comparison among possible types of changes was done to permit a better understanding of patient priorities.

Method

Subjects

The participants were 686 francophone couples who consulted for the first time at the fertility clinic of a large metropolitan hospital. Both partners underwent a battery of psychosocial tests immediately after the medical interview. Couples were invited to repeat psychosocial testing at 6-month intervals over a 24-month period as part of a longitudinal study. Participation was strictly voluntary. In order to assure a high participation rate, however, couples were reimbursed for travelling expenses up to \$30 for each psychosocial evaluation, including the one during intake.

The summary of participation rates in the psychosocial study and rate of abandonment of medical treatment is presented in Table 1.

At each successive phase of assessment, the number of couples for whom data were available for both male and female, and who were actively involved in treatment or investigation, decreased. The numbers of couples were as follows: intake — 686; 6 months — 408; 12 months — 277; 18 months — 202; and 24 months — 174. In order to increase the sample size of couples in prolonged treatment, 98 couples who had received at least 24 months of treatment, but who had not previously participated in the research, were tested; they were called the quasi-experimental group. The number of quasi-experimental couples per treatment condition was as follows: medication — 3; AID — 23; IVF — 49; and artificial insemination with husband's sperm (AIH) — 23.

Procedure

During the first few minutes of medical intake, a gynaecologist explained the purpose of the medical and psychosocial examinations, and

emphasized that results from the latter would remain strictly confidential and would not be used to select couples for medical treatment, in line with Quebec Social Affairs Task Force recommendations (Quebec, Comité de travail sur les nouvelles technologies de reproduction humaine 1988). All participants were evaluated, using a standardized interview schedule, by one of four senior gynaecologists. Consistent with practices in other infertility research centres, variables such as the duration of infertility, medical history of both partners, previous treatment attempts, et cetera, were recorded (Medical Research International et al. 1991). After the first medical interview (45 to 90 minutes), the couple took a 10-minute break, and then met with one of four female psychosocial evaluators who had completed at least two semesters at the Master's level in counselling or clinical psychology as well as a practicum in couple assessment. The psychosocial evaluator spent 10 minutes establishing a rapport with the couple, describing the functioning of the fertility clinic, and explaining the purpose and nature of the psychosocial and medical assessments. The couples signed the consent form (Appendix 1), then completed self-report measures on diverse areas of psychosocial functioning.

Description of Treatments

Participants received the following types of treatment: medication, surgery, AID, IVF, AIH, or no treatment.

Measures

The first task of patients was to complete a questionnaire concerning the history of their infertility, their perception regarding prognosis of treatment, psychosocial services received, strength of desire for a child, et cetera, as well as sociodemographic data (Chatel et al. 1987) (Appendix 2).

Psychiatric Symptom Index*

*The Psychiatric Symptom Index** (Illfeld 1976) is a shortened and modified form of the Hopkins Symptom Checklist (Lipman et al. 1969). It was translated into French and standardized on more than 16 000 French Canadians in Quebec (Kovess 1982). Subjects rate, on a scale of 0 to 3 (absent to very often), their experiences of 29 symptoms of psychological distress during the previous seven days. This instrument generates an overall score from the 29 items and four subscale scores — depression, anxiety, cognitive disturbances, and hostility. Subject responses for full scale and subscales are calculated and converted to a 100-point scale. The large-scale Health Québec study (Tousignant and Kovess 1985) indicated that the cut-off for the upper 15% of the population (most distressed) was 25 and above, on the global score. In the present study, the Cronbach

* For information on how to obtain English and French copies of the studies marked with an asterisk, please contact the author of this paper.

(1951) "alpha" (measure of internal consistency) on the total scores of the Psychiatric Symptom Index reached $r = 0.92$ for both women and men; for six months, the temporal stability coefficients attained were 0.50 for men and 0.67 for women.

Rosenberg Self-Esteem Scale*

*The Rosenberg Self-Esteem Scale** (Rosenberg 1965) is a widely used, well-established 10-item questionnaire that measures feelings about oneself. There are four response choices for each question, ranging from "strongly agree" to "strongly disagree." Scores range from 10 to 40, with higher scores reflecting lower levels of self-esteem. The scale was translated into French and standardized by Vallières and Vallerand (1990). Scores above 23 are judged to be in the clinical range of distress (ibid.). In the present study, alpha reached 0.82 for women and 0.80 for men; for six months, temporal stability coefficients attained were 0.50 for men and 0.67 for women.

Psychological State of Stress*

*The Psychological State of Stress** (Lemyre and Tessier 1988) is a questionnaire developed to evaluate the degree to which persons experience stress. Patients rate the behavioural, cognitive, or affective signs of stress for 27 eight-point items. Final scores range from 27 (absence of stress) to 216 (maximum stress). In a study of French-Canadian adults, a score of 104 and above was found to represent the upper 15% of distressed persons. In the present study, alpha reached 0.94 for women and 0.93 for men; for six months, the temporal stability coefficients attained were 0.66 for men and 0.64 for women.

Dyadic Adjustment Scale*

*The Dyadic Adjustment Scale** (Spanier 1976) is a widely used 32-item self-report questionnaire on marital satisfaction, which yields overall scores that range from 0 to 151. The generally accepted cut-off on the English and French (Baillargeon et al. 1986) versions is 100, with scores of below 100 designated as maritally distressed. In the present study, alpha reached 0.91 for women and 0.90 for men; for six months, the temporal stability coefficients attained were 0.75 for men and 0.80 for women.

Index of Sexual Satisfaction*

*The Index of Sexual Satisfaction** (Hudson et al. 1981) is a 25-item instrument designed to measure couples' current level of sexual satisfaction, which was translated into French by Comeau and Boisvert (1985). Subjects rate the accuracy of 25 statements about various dimensions of sexual satisfaction on a five-point scale ranging from 1 (rarely or never) to 5 (usually or all the time). The final score is the sum of the items, with a maximum of 125. Twenty-five is subtracted from the final result, giving scores that range from 0 (maximum satisfaction) to 100 (maximum dissatisfaction). Generally, scores over 30 are considered to be in the clinical range of sexual difficulty (ibid.). In the present study, alpha

reached 0.92 for men and women; for six months, the temporal stability coefficients attained were 0.72 for men and 0.76 for women.

Inventory of Socially Desirable Responding*

*The Inventory of Socially Desirable Responding** (Paulhus 1984) is composed of two subscales of 20 items each and is designed to measure (a) a person's tendency to give biased responses about the self (self-deception) and (b) a person's tendency to make a favourable impression on others (impression management). Each subscale has 20 seven-point scale items. The most recent recommendation of the originator of this text is to reverse the negatively keyed items, then add one point for each extreme response (6 or 7). Therefore, for each subject the total score on self-deception and impression management can range from 0 to 20 (Paulhus 1991).

Brief Measure of Social Support*

*The Brief Measure of Social Support** (Sarason et al. 1983; translated into French by de Man et al. 1986) is composed of six questions about social support. For each item, the subject first rates the number of people on whom he/she can depend for social support, and then the degree of satisfaction with the support offered (from +3 [very satisfied] to -3 [very dissatisfied]). The final score is expressed by averaging the subject's responses from each of the six items and overall number of sources of support and level of satisfaction. In the present study, alpha reached 0.87 (number of sources) and 0.90 (satisfaction) for women and 0.85 and 0.84 for men; for six months, the temporal stability coefficients attained were 0.68 and 0.42 for men and 0.63 and 0.39 for women.

Evaluation of Services

The psychosocial evaluation at six months was identical to the initial evaluation, with three additions. The team developed three self-report instruments to tap (a) satisfaction with services, (b) suggestions for improved services (not yet analyzed), and (c) patients' ratings of treatment intrusiveness.

Perceived Intrusiveness of Fertility Treatment Scale

The Perceived Intrusiveness of Fertility Treatment Scale (Wright and Sabourin 1988 — Appendix 3) was developed after consulting the available literature at the outset of this study (August 1987). The team developed an instrument that would resemble, as much as possible (while reflecting the specific experiences associated with infertility treatment), the only other measure of intrusiveness of medical procedures, one developed for renal diseases (Devins et al. 1983). Instructions were as follows: "Please indicate the extent to which the medical treatment undergone over the last six months with respect to your infertility (or the treatments undergone by your partner) have interfered with, hindered, or imposed upon the different aspects in your life listed below." Subjects were asked to circle a number (from 1 [not at all] to 7 [very much]) beside the description of each life sphere. The original

areas used by Devins and colleagues, along with others cited in clinical and popular literature concerning infertility, were submitted to four experienced clinicians. The dimensions that were ranked as distinct and most important were retained in the final version of the scale.

In order to carry out the initial investigation of the perceived intrusiveness of fertility treatments and to compare results with the only other published work in the area of treatment intrusiveness, items that covered similar life domains were grouped together (calculated and averaged) around the five life domains that Devins et al. (1990) adopted: (1) physical well-being (health, sleep, diet); (2) work outside the home and at home, finances, domestic work, division of responsibilities; (3) marital, sexual, and family relations; (4) recreational and social relations (leisure, relaxation, and social relations); and (5) other (social support, self-esteem, and social acceptance). Since clinical publications suggest that fertility treatments also intrude on patients' morale (Mahlstedt 1985) and because Folkman and Lazarus (1984) suggested that this might be an important area to track in stress research, one additional question tapped this dimension. The subscales produced the following levels of internal consistency (α): (1) physical health, male = 0.80, female = 0.81; (2) work and finances, male = 0.64, female = 0.49; (3) marital, sexual, and family, male = 0.87, female = 0.87; (4) recreation and social relations, male = 0.84, female = 0.81; (5) other, male = 0.84, female = 0.81. For the total scale, α reached 0.85 for both men and women.

Patient Satisfaction Form

The Patient Satisfaction Form (Sabourin et al. 1991 — Appendix 4) is a 31-item questionnaire that assesses consumer satisfaction with fertility treatment. The Patient Satisfaction Form evaluates many dimensions of service delivery that are primary targets of satisfaction ratings by clients: (1) information as to probable diagnosis, kind/type of services and their side-effects, prognosis; (2) quality of service; (3) amount, length, or quantity of service; (4) attitudes of medical staff; and (5) general satisfaction with the clinic. There are seven response choices for each question, scored 1 through 7. Scores range from 31 to 217, with higher scores reflecting higher satisfaction with services.

The Patient's Suggestions for Improvements in Services

Patient's Suggestions for Improvements in Services is a 20-item questionnaire (Sabourin and Wright 1988 — Appendix 5) concerning the type of changes that might be made in the fertility clinic services. It was developed on the basis of clinic experience and literature reviews to survey patients' suggestions, such as increased access to support groups, more information on prognosis from physicians, and greater inclusion in decision making. Patients rated each item from 1 (not important) to 7 (very important).

The Telephone Interviews re: Reasons for Abandoning Treatment

Telephone Interviews re: Reasons for Abandoning Treatment is a questionnaire (Sabourin and Wright 1990 — Appendix 6) concerned with the cessation of fertility treatment. Of the 686 couples originally assessed at intake, a total of 467 dropped out of medical treatment within 24 months, without pregnancy. To better understand patients' reasons for abandoning treatment, four experienced psychologists attempted to make telephone contact with each couple that dropped out. After explaining the purpose of the survey and assuring confidentiality, the interviewer asked 10 questions (ibid.) about length of treatment, point of drop-out, treatment that preceded drop-out, whether their physician had recommended a subsequent treatment, what that treatment was, and the overall reason for quitting. Finally, patients were asked to rate, from 1 (not important) to 7 (very important), 16 reasons that influenced their decision to terminate (e.g., couple problems, lessened desire for a child, treatment inflicts too much physical or psychological suffering).

Results

Description of the Initial Sample

The age of male participants ranged from 18 to 56 years and that of female patients, 17 to 43 years, with women $\bar{x} = 30$, $SD = 4.67$ and men $\bar{x} = 32$, $SD = 5.55$. Average yearly income for men was \$35 311, $SD = \$34\,759$; and for women, \$20 024, $SD = \$15\,739$. Both men and women had an average of 13 years of formal education. The average duration of infertility prior to intake was 36.2 months, $SD = 28.1$. Although 42.4% of the subjects had had one pregnancy, only 21.7% of those pregnancies had lasted more than 20 weeks. Only 19.9% of the participants had at least one living child. In the present sample, six months after intake, 52.2% of the couples were diagnosed as female cause infertility; 15.5% male cause; 9.4% mixed cause; and 22.2% unknown cause.

Evolution of Psychosocial Adjustment in IVF Patients over Time

Table 2 reports the means and standard deviations for men and women participants (including quasi-experimental group) at each of the five phases of testing for five questionnaires (marital adjustment, sexual satisfaction, self-esteem, psychiatric symptoms, and psychological stress) according to treatment received. Social desirability scores for the six treatment groups are presented in Table 3.

A variety of statistical analyses were carried out in order to explore the data: computation of a correlation matrix for demographic data and psychosocial data; analyses of covariance using certain demographic variables and/or social desirability scores as covariates; multivariate

analysis of variance on couples measures (marital and sexual) versus individual (psychiatric, self-esteem, stress); simple analysis of variance (sex, by time, by treatment); and direct comparisons between means. Statistically, other analyses led to the same conclusions generated by the simple $2 \times 3 \times 2$ analyses of variance. Only the latter will be reported here, as the links between the analyses and specific cell means in each table are easier for the reader to interpret.

General Findings

At intake, infertile women were more distressed than their husbands on measures of psychiatric symptoms, self-esteem, and stress, but there were no significant differences on measures of marital¹ and sexual adjustment (Table 4A) between the men and the women.

Scores on the Psychiatric Symptom Index were higher for both infertile men and women than population norms, but the level of distress was not so high that the means were in the clinically distressed range (Table 4B). For an in-depth discussion of these results, see Wright et al. (1991). Neither men nor women from infertile couples had higher than normal distress scores on measures of marital adjustment, sexual satisfaction, self-esteem, or stress. In fact, the average scores on the measure of marital adjustment of the overall sample ($\bar{x} = 120.5$, $SD = 13.8$) for the 686 couples at intake placed most of the couples in the very well adjusted range of marital happiness, a result consistent with other research.

At intake, women from infertile couples had significantly higher scores ($\bar{x} = 9.6$, $SD = 3.5$) than their partners ($\bar{x} = 8.8$, $SD = 3.6$) on the impression management scale of the measure of social desirability (Table 3, $F(1,683) = 6.09$, $p < 0.015$). Men at intake were slightly higher than women at intake on the self-deception scale, but the difference was not significant. The impression management and self-deception scores of infertile couples were significantly higher than those obtained from a study of 884 religious couples and 100 college students. However, scores from the impression management scale of infertile couples were not significantly lower than mean scores of 48 members of Alcoholics Anonymous ($\bar{x} = 11.2$, $SD = 4.9$) (Paulhus 1991).

Taken as a whole and independent of treatment received, only two psychosocial measures revealed a significant deterioration over time (Table 5): marital adjustment ($F(4,484) = 6.29$, $p < 0.0001$) and frequency of sexual relations ($F(4,452) = 17.61$, $p < 0.0001$). At the 24-month assessment, men reported less marital adjustment and sexual satisfaction than at intake. Women reported a significant drop in marital satisfaction from intake to 24 months ($F(4,492) = 3.3$, $p < 0.007$).

¹ Lower score, poorer adjustment; all other questionnaires: higher score, poorer adjustment.

Comparison Between Couples Who Became Pregnant Versus Couples Still Infertile at Each Stage of Testing

The pregnancy rate for women who participated in the present study, per state of testing, was as follows: 6 months, $62/408 = 15\%$; 12 months, $75/277 = 27\%$; 18 months, $75/202 = 37\%$; and 24 months, $81/174 = 47\%$.

Six months

Women who became pregnant were significantly less distressed on measures of psychiatric symptoms ($t(101,14) = 2.69$, $p < 0.008$), marital adjustment ($t(80,94) = 1.96$, $p < 0.05$), stress ($t(93,10) = 3.73$, $p < 0.0001$), and self-esteem than women who did not become pregnant (Table 5). No differences were found for the male partners concerning these variables.

Twelve months

Women who had not become pregnant were less sexually satisfied ($t(128,52) = 2.23$, $p < 0.05$) than pregnant women (Table 5). However, partners of pregnant women reported higher stress than those of women who were still infertile ($t(128,16) = 2.01$, $p < 0.05$.)

Eighteen to 24 months

No significant differences were found between the pregnant and infertile groups at this point (Table 5).

Miscarriage Versus Still Infertile

Although the sample size was small, Mann-Whitney tests revealed more distress in women who did not become pregnant than in women who miscarried, more psychiatric symptoms and stress at 12 months, and differences in marital adjustment at 18 and 24 months (Table 5).

Evolution of Psychosocial Response in IVF Patients over Time

In order to evaluate whether the level of psychosocial distress of IVF patients increased with treatment duration, analyses of variance and comparisons between means were carried out.

Patients who received IVF for more than 24 months (quasi-experimental design with 98 couples) were contrasted to IVF patients 24 months after intake (20 couples). Only one contrast proved significant: women who had received more than 24 months of IVF treatment (quasi-experimental group) were more sexually dissatisfied than women after 24 months of IVF (see Table 2).

Women and men with more than 24 months of treatment were significantly less satisfied sexually than participants at intake (women, $t(38,75) = 2.10$, $p < 0.05$; men, $t(48,91) = 2.22$, $p < 0.05$). In all the other comparisons conducted between lengthier versus shorter IVF treatment or between a given follow-up time and intake, no results revealed significant differences in distress as treatment progressed.

In the IVF treatment, there were some increases in mean psychiatric symptom and psychological stress scores for both men and women between intake and the first evaluation (see Table 2). However, the differences did

not prove statistically significant. The relatively small sample sizes and high variability affected the chance of finding statistically significant differences.

Percentage of Patients Above Clinical Cut-off Point

The proportion of individuals above the normative 85th percentile was calculated for the sample scores for the Psychiatric Symptom Index (Table 6) and the four subscales of this measure. The percentage of IVF males above the 85th percentile went from 9% (two men) to 40% (eight men) from intake to 12 months later. IVF women above the 85th percentile on the Psychiatric Symptom Index started at 14% and went to 32% at 6 months, 35% at 12 months, and 43% at 18 months. Interestingly, the rate dropped for women at 24 months to 15%.

Rather remarkable results occurred on the hostility subscale of the Psychiatric Symptom Index for the whole MFT sample as measured at 12 months post-intake: 57% of men were above the 85th percentile, and 63% of women were above the 85th percentile. There was no evidence that IVF patients felt more hostile than patients in other groups. These data would suggest that, on the average, more than half of patients in fertility clinics experience strong feelings of hostility. It would be interesting to know how patients cope with their hostility. Is it directed toward staff, their spouses, or themselves? This would be an important question for future research.

On the scale of sexual satisfaction, there was little indication (Table 6) that more IVF patients were above the clinical cut-off point than patients who received other MFT, nor was there consistent change over time. More sexual problems were associated with AID, according to percentile data. Very few patients, including IVF respondents, scored within the distress range (-100) on the marital adjustment scale. Such data confirm that most fertility clinic patients perceive their marriage as very well adjusted. The number of MFT couples in the scoring in the distressed range rose from 6% at intake to 11% at 24 months. More IVF men than women responded in this way, but small sample sizes prevent generalization of these results.

Patients' Perception of Chances of Successful Treatment

Patients were asked to rate their chances of conceiving a child at each assessment. Women's scores were as follows: intake 56%, 6 months 45%, 12 months 34%, 18 months 30%, and 24 months 26%. Men's rates were as follows: intake 60%, 6 months 46%, 12 months 34%, 18 months 26%, and 24 months 31%. Patients' ratings of their doctor's perception of prognosis were more pessimistic: at intake 50%, almost identical at 6, 12, and 18 months, but more optimistic at 24 months for both men and women — 34% compared with 26% for women and 31% for men on their own perception of prognosis. Comparisons between mean prognosis ratings revealed that only the drop from intake to 6 months was significant.

The perceptions of prognosis of IVF versus other treatment groups were compared, because several studies have found that IVF patients overestimate chances of success (Callan et al. 1988; Leiblum et al. 1987).

Males reported the following chances of success: intake 50%; 6 months 25%; 12 months 19%; 18 months 17%; and 24 months 9%. IVF females reported the following chances of success: intake 55%; 6 months 38%; 12 months 17%; 18 months 17%; 24 months 8%. Given actual success rates (Medical Research International et al. 1991), the present study confirms that expectations are overly optimistic at intake but become more realistic over time in treatment.

Intrusiveness of IVF

The average value of the perceived intrusiveness scale for each of the six treatment groups at 6, 12, 18, 24, and 24+ months is presented in Table 7. An examination of the mean values reveals four conclusions supported by analyses of variance:

- on average, women report that fertility treatments and diagnosis are more intrusive than do their husbands ($F(1) = 28.24$, $p < 0.0001$). The strongest sex difference was found for IVF: \bar{x} women = 75.75, $SD = 24.99$; \bar{x} men = 57.46, $SD = 19.73$);
- IVF is perceived as significantly more intrusive ($\bar{x} = 66.59$, $SD = 24.02$) than the other treatments taken together ($\bar{x} = 41.78$, $SD = 22.63$; $F(5) = 8.39$, $p < 0.001$);
- for women receiving IVF, there was no significant overall increase or decrease in intrusiveness scores with continued duration of treatment; in fact, for women who remained in treatment, there was an average drop in perceived intrusiveness over time: \bar{x} at 6 months = 79; \bar{x} at 12 months = 74; \bar{x} at 18 months = 69; \bar{x} at 24 months = 62; and \bar{x} at 24+ months = 63 (Table 7); and
- the 17 items of the perceived intrusiveness questionnaire were regrouped into six subscales. For all six treatment modalities, as shown in Table 8, patients reported that of all six life domains, morale was the most affected. The order of severity of disruption for IVF patients was as follows (starting with most severe): morale ($\bar{x} = 5.14$), work ($\bar{x} = 4.86$), recreation ($\bar{x} = 4.45$), marital ($\bar{x} = 4.30$), physical ($\bar{x} = 3.80$), and self ($\bar{x} = 3.59$). Table 8 indicates which of these differences between means are statistically significant. It is interesting to note that IVF patients report that their morale is significantly more disrupted than other spheres of their life — physical health, marital adjustment, recreation, and self-expression — which underscores the importance of providing support services for the psychosocial functioning of IVF patients. The least disrupted domain was physical health, but a good deal of media coverage and medical attention has focussed on this particular dimension.

Satisfaction with IVF and Other Treatments

Means after 6, 12, 18, and 24 months for each of the 31 items of the Patient Satisfaction Form are reported for women (Table 9A) and men (Table 9B). In addition, a dissatisfaction score was produced for each item by computing the percentage of subjects who indicated that they were not satisfied with the rated dimension (see Table 10).

Both men and women consumers of infertility treatment seemed quite satisfied with most aspects of their experience (Tables 9A and 9B). Average scores for men and women at each of four phases of testing fluctuated from a low of $\bar{x} = 3.43$ for information received about alternative services in the community (adoption) to a high of $\bar{x} = 5.90$ for nurses' attitudes at 24 months. The average satisfaction rating for both men and women at each of four phases of testing was above 4.67. Since a seven-point scale (from not at all satisfied [1] to very satisfied [7]) was employed, the author concludes that the average consumer was at least moderately satisfied throughout the 24 months of contact.

However, a significant and consistent group of consumers was dissatisfied with some aspects of the service (Table 10). For each of the four phases of testing, at least 10% of women were dissatisfied on 16 of 31 items at 6 months; 15% at 12 months; 16% at 18 months; and 15% at 24 months. Men's dissatisfaction rates closely paralleled women's, except at 24 months, where fewer men were dissatisfied. Six areas consistently yielded dissatisfaction ratings from 20% or more of the women at each of the four phases of testing. In order of highest average dissatisfaction score for women over 24 months, they were as follows: information offered about other services available in the community (such as adoption: \bar{x} dissatisfaction = 41%); information about secondary effects of treatments (\bar{x} dissatisfaction = 23%); information about prognosis (\bar{x} dissatisfaction = 23%); time spent in waiting room (\bar{x} dissatisfaction = 22%); number of different doctors seen (\bar{x} dissatisfaction = 22%); time spent talking with doctors (\bar{x} dissatisfaction = 20%). Emotional support from medical staff reached a 20% dissatisfaction rate for women at 18 months post-intake.

Although slightly fewer men expressed dissatisfaction, they were most affected in the same six areas as women.

There was little evidence that average satisfaction ratings or percentage of consumer dissatisfaction fluctuated over time. In short, satisfaction scores did not appear to depend on duration of treatment.

The total satisfaction ratings of IVF patients, in contrast with all other treatment groups pooled together, are shown in Table 11A for women and Table 11B for men. An examination of the means from the four phases of testing yields no evidence of significant differences in satisfaction ratings among IVF and other treatment groups at any point in time. The same comparisons among IVF and other treatments were completed for the seven

items that yielded the highest dissatisfaction scores. Again there were no significant differences among treatments, and no changes over time.

Couples Who Abandoned Medical Treatment

Twenty-four months after intake of the original 686 couples, 174 were still in treatment and had completed the psychosocial evaluation (see also Table 1). A total of 16 couples stayed in treatment but at some point refused to complete the full psychosocial test battery. The team attempted to follow up all 512 cases of treatment abandonment by means of a brief telephone interview by an experienced psychologist (Appendix 6). One hundred and ninety couples were contacted by phone and agreed to respond. Of the 308 couples who were not successfully contacted, 277 had moved or changed telephone numbers and 31 did not respond after 10 telephone calls. Fourteen couples refused to respond without explanation. Thus the successful contact rate for 512 dropouts was 190 or 37%, which, although disappointing, is as high as or higher than that of other published studies in the area.

Of the 190 couples who agreed to respond, 29 had terminated treatment because of pregnancy, 17 had changed clinics, and 6 had divorced. The remaining 138 couples completed the telephone interviews.

Of the 138 respondents, 4 were men and 134 were women. The 138 couples had consulted at the clinic for between 1 and 24 months, for an average of 6.3 months. They had visited the clinic between 1 and 35 times, for an average of 4.8 visits. Ten percent terminated before completing the diagnosis, 26% during the diagnosis, 13% upon receiving the diagnosis, and 50% during treatment. The following treatments had been administered just before termination: AID 3%; AIH 5%; IVF 5%; medication and AIH 4%; medication 28%; and tuboplasty or laparoscopy 8%. Seventy-three percent of patients were advised by their physician to undergo another treatment; 27% had not been advised to do so, according to their response. The treatments recommended were IVF 45%, AIH 20%, tuboplasty or laparoscopy 10%, AID 9%, and medication 16%.

Motives for Terminating Treatment

Respondents were asked to state what importance 16 factors (Appendix 6, Question 10) played in influencing their decision to terminate contact with the clinic. For the 138 couples who quit without pregnancy and who did not attend another clinic, the average response rate on a scale from 1 (not at all important) to 7 (very important) is shown in Table 12.

The following factors are cited in order of importance in terms of means rating: (1) too much psychological suffering; (2) lack of dialogue with treating physician; (3) inefficacy of treatment; (4) lack of moral support from the medical team; and (5) lack of information about diagnosis, treatment side-effects, and prognosis.

Interestingly, in spite of the high ratings for psychological suffering and lack of dialogue or moral support from the medical team, couples who

terminated prematurely did not question the competence of the physician. This clear delineation between psychosocial factors and physician competence suggested that respondents were making distinct judgments about motives and not a global judgment (e.g., I'm disappointed with every aspect of my contact). This finding increased, at least partially, the confidence in the validity of the telephone follow-up data.

Relationship Between Reasons for Premature Treatment Termination and Other Psychosocial Measures

Correlation coefficients were calculated for the scores on the 16 possible motives for abandoning treatment and psychosocial data at intake and at 6 months.

The highest rated motive for treatment termination, psychological suffering, did not correlate significantly with *any* standard psychosocial measure administered at intake for women. Such results would suggest that their early treatment termination was not determined by an elevated level of psychosocial distress at intake. For the few men evaluated, treatment termination was correlated with sexual dissatisfaction only.

No significant correlations were found for the next rated termination motive, lack of dialogue with physician, with women's intake psychosocial data. Weakness of self-esteem was positively correlated with perceived inefficacy of treatment. No significant covariation was found for perceived lack of moral support from medical team or lack of information.

No significant correlations were found between the five most frequently cited motives for abandoning treatment and women's psychosocial data at 6 months. However, several significant relationships were found between motives for drop-out and satisfaction with service ratings on the one hand (Appendix 4) and request for improvement in services on the other (Appendix 5).

To reduce the amount of data, only the relationship between motives for abandoning treatment and 7 of 31 items that received the most frequent dissatisfaction scores (Nos. 8, 10, 14, 18, 21, 22, and 23) and 9 of the 20 most frequently mentioned requests for improved services will be reported here (Table 13). The four most frequently cited motives for patient-initiated treatment termination were predictably related to satisfaction with services on the one hand and requests for improvements on the other. The implications of these findings for modification of fertility clinic practices will be discussed later.

The link between motives for drop-out and duration of contact with clinic (months, visits) was also calculated. The only motive for drop-out that correlated positively with duration of treatment in months was psychological suffering ($r = + 0.2867$; $p = 0.001$). Apparently, the lengthier the treatment, the more psychological suffering was cited as a motive for treatment termination.

Did People Who Terminated Treatment Prematurely Differ from Those Who Continued?

Many opinions have been published as to whether couples who terminate treatment early are more or less psychologically distressed than those who persevere. In a study of the first 300 admissions to MFT, Fortier et al. (1992) found that couples who did not come back for a second interview (98 out of 300) more often already had one child, had lower family income, reported less social support, were less stressed (women), had a lower desire to have a child, perceived a lower desire to have a child in their partner, and were less optimistic about the efficacy of treatment than couples who continued.

To follow up this question, analyses of variance were performed on all psychosocial variables for intake and at 6, 12, 18, and 24 months as a function of whether a couple continued treatment or abandoned it at the subsequent phase of testing. These data are presented in summary form only:

- higher social support discriminated between those who abandoned treatment and those who persisted in their treatment at 6 months — the more social support, the more perseverance. But by the testing at 24 months, those with more social support had a higher tendency to terminate;
- higher family income was associated with higher perseverance at 6 months only;
- the higher the perceived chances of pregnancy according to the patients' view of the doctor's opinion, the more perseverance at 6, 12, 18, and 24 months;
- the stronger the desire for a child (and perception of spouse's strength of desire for a child), the higher the perseverance at 6 and 12 months. However, stronger desire for a child reported at intake and 6 months was associated with higher drop-out at 24 months;
- lower sexual satisfaction of husband was associated with abandonment of treatment at 6 months, as was inhibited sexual desire at 18 months;
- a strong tendency to project a positive image (impression management) for men and women, and self-deception for men, were associated with increased perseverance at 6 months;
- various requests for changes were associated with increased drop-out: (a) desire for more personalized information for decision making at 12 months; (b) desire for more information on psychological side-effects at 6 and 24 months;
- desire to be seen by a nurse or psychologist at intake, desire for greater access to support groups, and requests for more

information on secondary effects, prognosis, and psychological side-effects at 24 months were all significantly higher in patients who abandoned treatment than in those who persevered;

- couples who reported at 12 months that the fertility problem enhanced their life as a couple persevered more at 18 months; and
- interestingly, abandoned versus persisting participants did not differ on the measures of psychiatric symptoms or marital adjustment at any of the times tested.

Psychosocial Support Services Requested by Couples

As noted in Appendix 5, patients were asked at 6, 12, 18, and 24 months to suggest 20 possible improvements in services. The mean responses for each phase appear in Table 14A for women and Table 14B for men. Table 15 summarizes the percentage of men and women who indicated this was a high-priority change, with a score of 6 or 7 on a seven-point scale.

When averaged over four phases of testing, irrespective of treatment received, and combined for men and women, the most important recommendation was that the medical team provide more information on the following: prognosis ($\bar{x} = 6.1$); the diagnosis (etiology) ($\bar{x} = 5.9$); diverse treatment possibilities ($\bar{x} = 5.8$); length of the treatment ($\bar{x} = 5.7$); and diverse physical exams ($\bar{x} = 5.6$). This information might permit more personalized decision making, and could come through more lengthy discussions with the medical team or documentation. More information on the possible psychological side-effects of the medical treatment was requested ($\bar{x} = 5.5$). More frequent consultation on medical decision making was considered desirable ($\bar{x} = 5.4$), as was more delicate physical contacts ($\bar{x} = 5.2$) and more moral support ($\bar{x} = 5.2$).

The following changes were rated as less important: offer group information sessions ($\bar{x} = 5.1$); be received by nurse and psychologist at intake ($\bar{x} = 4.9$); receive information from other sources ($\bar{x} = 4.7$); have more time for decision making ($\bar{x} = 4.6$); have access to a psychologist ($\bar{x} = 4.3$); have access to a support group ($\bar{x} = 4.2$); and improve the setup of the waiting room so as not to be with women who are there for abortion ($\bar{x} = 4.1$).

The strongest suggestions consistently underline the desire of patients to have more dialogue with their treating physician in order to increase the quality of decision making. In short, considering the 10 items that received the highest average scores, the first priority of the patients is to be better informed. Requests for more moral support by the medical team, access to a nurse and/or psychologist at the outset of or during treatment, or access to a support group were all rated above the mid-point on the seven-point scale, but were not scored as high as requests for more information on

medical decision making. Increased availability of psychological services at the outset was rated as a priority by 50% of women, and increased availability of psychological services during the course of treatment was highly recommended by 35% of women.

Table 16 summarizes the percentage of men and women at each stage of testing who expressed a need for couple therapy or sex therapy, and the percentage of men and women who had received couple or individual therapy in the later phases of MFT; it shows that a range of 7-21% requested it. Given the much higher interest rate expressed in more general psychological services (Request No. 2: 50% of women and 35% of men placed this as a high priority), it is clear that fertility patients draw a distinction between general psychological support and therapy.

Changes in Requests for Services over Time

Analyses of variance and subsequent *t*-tests were completed to evaluate whether there were significant changes over time in requests for services. There were significant changes over time for only four items:

- support groups: $F(3,342) = 3.03$, $p = 0.029$ (significant increase from 6 to 12 months);
- access to psychological services: $F(3,342) = 6.27$; $p = 0.0001$ (significant increase from 6 to 12 months);
- change waiting room setup: $F(3,333) = 10.35$, $p = 0.0001$ (increase from 12 months to 18 and 24 months); and
- be interviewed by nurse and psychologist at intake: $F(3,336) = 3.71$, $p = 0.012$ (increase from 6 to 12 months).

To summarize, most requests for changes remained stable over time. Those requests that changed occurred mainly in the second 6 months, and three out of four of these concerned increased requests for psychosocial services.

Requests of IVF Patients

Requests for changes in services are reported independently for the six treatment groups at each of the four phases of testing for women in Table 17A and men in Table 17B. Time and space do not permit a detailed analysis of the wealth of information. Small sample sizes do not permit statistical tests for evolution over time, but the following requests for changes appeared to reflect the strongest increases over time for IVF patients: men requested more psychological services, documentation, and information on different treatment options. They wanted to be consulted in decision making, to change the waiting room setup, to have more time for decision making, and to be seen by a psychologist and/or nurse at intake. Women requested an increase on only one item, psychological services.

Analyses of variance of recommended changes by IVF versus other participants revealed a variety of significant differences at certain phases

of testing, but, interestingly, the significant differences were found only with the male partner. On Request Nos. 1, 2, 6, 7, 8, 18, 19, and 20, male IVF patients voiced stronger recommendations at a variety of phases of testing than other groups, with several interesting exceptions: AID males rated as high on requests for psychological services; AID men rated higher on requests for moral support (except at intake); AID males scored higher than other groups on requests to be seen at intake by a nurse and/or psychologist.

In general, women who received IVF did not voice stronger requests for changes in services than women who received other treatments.

Discussion

The Evolution of Psychosocial Adjustment in IVF Patients

Previous Research

Most clinical research, including the uncontrolled studies, seems to suggest that the present study would be expected to find a significant drop in mental health and couple adjustment in men and, particularly, women who received MFT, especially IVF. However, a survey of results of the 13 better controlled studies published to date leads to a more cautious prediction.

Present Findings

The present study found that, in general, irrespective of treatment condition, there was a significant drop from intake to 24 months later on measures of couple adjustment and sexual satisfaction and frequency of sexual relations. But there was no significant increase in average scores on psychiatric symptoms, perceived stress, or self-esteem problems. Social desirability scores were high at the outset, especially in women, but impression management scores dropped significantly over time. Both men and women who received IVF for more than 24 months reported lower sexual satisfaction than patients with shorter treatment periods. The only evidence for psychosocial deterioration associated with IVF was for a measure of sexual satisfaction, though IVF was rated as much more intrusive in the daily lives of the patients than other treatment modalities, and examination of the percentage of patients scoring above clinical cut-off points leads to the suggestion that there were steady increases in distress for some. Possible explanations for the failure to find strong evidence for psychosocial deterioration of MFT patients, and IVF patients in particular, will now be discussed briefly.

Time of First Testing

Some authors have suggested that during the initial work-up, the highest level of psychological disturbances, especially anxiety and stress, is in the first 24 hours, and that as the investigation progresses, the distress drops. Daniluk (1988), using a repeated measure design, found that the highest individual distress levels at intake dropped over the next weeks as the investigation proceeded. No significant changes were noted for most groups of patients in marital or sexual relations.

If this hypothesis is true, psychosocial distress scores would be temporarily elevated during the first visit or two, and then drop during diagnostic tests, but would rise again as treatment progressed. Thus, the present study's fixed time measure at intake (24 hours) and six months later could hide the subsequent rise that would occur as treatment began.

Fixed-Interval Testing Hides Fluctuation in Distress

In an excellent study, Newton et al. (1990) found significant increases in depression and anxiety from pre- to post-unsuccessful IVF (testing occurred three months before and three weeks after the first IVF trial). These data suggest that if psychosocial testing occurred close to specific stressful clinical events (e.g., receiving news that treatment failed, receiving recommendations from the doctor that treatment is no longer indicated, couple or one spouse decides treatment is no longer worthwhile), it would yield much higher psychosocial distress scores. The present research, designed to respect grant budgets and also to keep time intervals constant, may have reduced our ability to detect the amount of psychosocial distress.

Many Couples Decompensate After They Terminate Treatment

The present data concerning social desirability suggest that both sexes engage in higher than average self-deception throughout their treatment. Abundant literature on coping responses suggests that a certain amount of self-deception can be a helpful response in many situations. For example, given that IVF succeeds with at best 25% of couples, just to undertake treatment requires that spouses deny that they may be in the 75% that will fail. It is highly possible that once they have repeatedly failed with IVF, this coping mechanism is no longer adaptive. Once this coping mechanism is abandoned and treatment terminated, many patients would likely be much more in contact with their grief at being permanently childless; some would likely experience deterioration in individual and couple adjustment, at least on a short-term basis.

Other Explanations

Another possible explanation for lack of strong evidence for psychosocial deterioration in patients is that infertile couples may project a positive image to the medical and psychological team in order to be accepted in the program. A consequence of a high tendency to present a positive impression of one's psychosocial distress during treatment would be the camouflaging of existing distress.

Another explanation is that couples who persist with IVF may be particularly resilient. In addition, it is likely that gynaecologists working in fertility clinics try harder, because they believe in the right of every couple to have a natural child.

Finally, the use of group mean data at each phase of testing may have masked the presence of a high-risk, high-distress group; the small sample size available at later testing, and the use of standard questionnaires rather than in-depth interviews, could also be responsible for lack of evidence of distress in patients.

Conclusion

Given the above considerations, the clinical literature on the psychosocial distress experienced by certain couples, and the findings of Newton et al. (1990), the present author concludes that the present study underestimated the amount and type of psychosocial distress experienced by certain fertility clinic patients, and IVF patients in particular. Not all patients are at risk, but a certain significant portion are. Practices in many clinics, including the present one under study, could be modified to better care for the high-risk patients.

Recommendation for Improvements in Fertility Clinics' Capacity to Meet Patients' Psychosocial Needs

1. *Increased information:* Increase the amount of information presented to the patients about the biophysical and psychosocial aspects of their situation, such as etiology, certainty of diagnosis, nature of tests, treatment options, prognosis of each option, specific nature of treatment regime (given patients' diagnosis) and possible physical consequences, a description of periods of increased stress during the fertility investigation/treatment (Seibel and Levin 1987), various coping reactions, examples of natural emotional reactions, signs of elevated individual or couple distress, et cetera. Such information could and should be presented in a consistent (no conflict between members of the team) fashion by treating physicians, nurses, mental health professionals, literature, and audiovisual aids.
2. *Quality decision-making processes:* Increase the quality of couples' decision-making processes. The clinical team, particularly the treating physician, must encourage the couple to carefully weigh the pros and cons of various options available from different treatment regimes — including waiting several months or years before treatment begins, considering adoption, or choosing to be childless. There are a growing number of clinical (Klock and Maier 1991; Taylor 1990) and scientific (Callan et al. 1988; Frank 1990) data concerning criteria couples use

to decide to commence or, to a lesser extent, terminate IVF. Mental health professionals with appropriate training could supply self-administered materials on how to improve the quality of couple decision making. One of the key objectives of psychosocial support, couple and/or group meetings, could be to enhance decision making.

The objective is to empower each couple to make the best decision for their given situation. This objective is rendered difficult to achieve by a variety of factors specific to MFT. For example, average success rates per trial of IVF are available for participating clinics (Medical Research International et al. 1991), but actual success rates vary across clinics and as a function of the medical history and age of each woman. As a result, physicians and other members of staff might present probability of success of treatment differently. Also, several studies have found that MFT patients consistently overestimate chances of success (Callan et al. 1988; Leiblum et al. 1987).

Couples need to know that many pros and cons for each alternative decision are tinged with emotion and are not easy to verbalize, even for the very mature and verbally skilled individual in a trusting relationship. Men and women react differently to various possible events throughout their treatment (denial, hyperactivity, highly supportive, information-seeking, sexual withdrawal, lack of communication) (Draye et al. 1988; Stanton 1991), and this needs to be factored in.

Physicians have received little training concerning how to share the decision-making process. In addition, the traditional medical model encourages the desire to cure illness, and many physicians trained to treat might have difficulty describing the disadvantages associated with IVF.

In spite of the above hurdles, the gains accrued by increased involvement of couples in decision making could improve the doctor/patient relationship and the general reputation of fertility clinics as well as clients' (and professionals') mental health. Lower premature drop-out rates and improved doctor/patient relations could lower stress, which has been linked to fertility parameters in certain studies (Harrison et al. 1987; Giblin et al. 1988; Modell et al. 1990).

3. *Destigmatize psychosocial distress and psychosocial services:* Fertility clinic patients and many gynaecologists see as undesirable natural and common psychosocial reactions to the experience of being infertile and to treatment. Meeting psychosocial needs and empowering client decisions may help overcome this problem, but the role of the mental health professional must be introduced early and in very clear terms. Given the results in the present study concerning high social desirability (impression management) scores of infertile patients as well as greater openness to psychological support and information as

opposed to therapy, all members of the team can reduce the stigma associated with taking advantage of psychosocial services. They could also underline that clinical studies indicate that couples who opt for psychosocial services benefit from a more constructive and less stressful experience.

4. *The mental health professionals could routinely meet all new patients:* Several authors now advocate that mental health professionals meet all new patients during admission (e.g., Klock and Maier 1991). Various roles have been defined: assessment, information, preventive counselling, identification of high-risk candidates, and the creation of constructive relationships. Mental health professionals working in fertility clinics not only need specialized training concerning biomedical parameters of the situation, including an understanding of the client and typical constructive and destructive responses, but also need to know how to inspire trust in the medical and paramedical staff, and often in distant or wary patients who may think, "this person will deny me treatment" (Wright and Sabourin, in press).

It is possible that routine scheduling of group meetings during the active clinic days could be more cost-effective than individual interviews. The mental health professional at ease with groups could use a relaxed, informal leadership style, while transmitting valuable information on diagnosis and treatment.

The psychosocial questionnaires and Patient Satisfaction Form could be explained, and the mental health professional could informally describe some of the typical psychosocial reactions to the condition of being infertile, the diagnosis, and the treatment. Types of psychosocial services available — assistance in couple decision making, stress management, information about other alternatives, counselling on long-term adjustment to childlessness, et cetera — could also be outlined.

5. *Separate the role of helper from selector:* Certain authors (Klock and Maier 1991) suggest that the same mental health professional who offers information and supportive service should also be the expert who decides whether a given patient is unsuitable to receive a given MFT. In the present author's view, the same mental health professional should not have both roles; the reduction in trust and use of psychosocial services triggered by the knowledge that the same professional could use confidential information to recommend denial of treatment would be too high a cost to pay.
6. *Gynaecologists offer an "exit" interview at treatment termination:* Approximately 70-80% of IVF couples will leave the clinic with unfulfilled expectations. Such couples, particularly the women, are at high risk for psychological problems. All couples who terminate treatment should therefore be invited to an exit interview with their

treating physician. During this time, the emotional issues, future plans, and present coping strategies could be explored in a supportive fashion. The available specialized psychosocial services could be outlined, and high-risk clients could be strongly encouraged to participate. The exit interview is probably one of the most stressful activities for gynaecologists. Specific courses should be offered to help identify the strong emotions involved for doctors and patients; effective coping strategies should be identified.

7. *Offer effective specialized psychosocial services:* As discussed in more detail elsewhere (Reading 1991; Wright and Sabourin, in press), there is abundant clinical literature concerning individual couple needs. In addition, a wide range of well-defined procedures can be offered once a differential diagnosis has been completed: stress management training, preventive sexual counselling, intimacy enhancement, dynamic couple therapy, problem-solving training, mutual support building, grief management, reorientation of life priorities, and organization of self-help groups. Again, the importance of adequate preparatory training to meet this challenge should not be underestimated.

Summary

Six hundred and eighty-six couples were evaluated at intake and invited back for repeated evaluation at 6-month intervals, for a total period of 24 months.

The Evolution of Psychosocial Adjustment in IVF Patients

Mean data revealed a decrease in sexual satisfaction and frequency of intercourse over time. The percentage of patients above the clinical cut-off point suggested that a specific subgroup of patients experienced more distress on measures of psychiatric symptoms as treatment progressed. IVF patients overestimated likelihood of successful pregnancy in the first 12 months, but had more realistic expectations in the last 12 months. Small sample sizes did not permit evaluation of successful IVF versus non-pregnant IVF patients. However, analyses from the overall sample indicated clearly that non-pregnant women experienced more distress on measures of psychiatric symptoms, marital adjustment, and stress than did pregnant women.

Intrusiveness of IVF

IVF was found to be more disruptive in six areas of life functioning, particularly patient morale, than all other treatment modalities; women found IVF to be more intrusive than men did.

Satisfaction with IVF Services

On a 31-item patient satisfaction scale, the overall score of participants was above the median (more satisfied than dissatisfied). However, some patients (approximately 20%) were dissatisfied with six elements of treatment, focussing on the lack of information and availability of doctors for discussion.

Couples Who Abandoned Treatment

Five hundred and twelve patients abandoned treatment before the 24 months was up. Of these, 29 were known pregnancies. The 138 dropouts contacted by phone cited psychological suffering associated with the treatment as the most common motive, followed by lack of dialogue with physician, ineffectiveness of treatment, lack of moral support, and lack of information from physicians. Patients who abandoned early did differ on a variety of psychosocial dimensions from those who persevered.

Psychosocial Support Services Requested by Couples

On a 20-item questionnaire, the most frequent requests were for increased information from physicians. Requests for specific support from psychologists were not scored as high. However, items related to psychological services were rated more highly with increased duration of treatment. Patients were clearly more open to supportive and counselling types of services than to psychotherapy.

Interpretations

A certain specific subgroup of MFT patients, and IVF patients in particular, may be at risk for psychosocial deterioration during and after treatment. The present research may have underestimated the intensity and frequency of psychosocial problems because of (1) fixed-interval testing, (2) concentration on 24 months of treatment instead of lengthier cases, (3) absence of psychosocial data on non-pregnant treatment terminators, (4) high socially desirable impression management to avoid exclusion from treatment, and (5) small sample sizes.

Seven modifications are suggested in psychosocial management: (1) increase amount and quality of information presented to patients from the outset; (2) improve the quality of couple decision making; (3) destigmatize psychosocial distress of infertile patients and present psychosocial services in a more positive light; (4) have a mental health professional involved at intake; (5) do not place the same mental health professional in the role of helper and selector; (6) offer an "exit" interview with a gynaecologist at treatment termination to offer support, explore psychosocial issues, and recommend psychosocial support services where indicated; and (7) be sure that the mental health professional attached to

the clinic has the competence and the job definition required to diagnose and offer the specialized services relevant for the infertile.

Future Research

Obviously, the costs and benefits of the implementation of each of the above recommendations must be evaluated through controlled research. Some clinicians contend that increased time spent on information transmission and decision making may not reduce subjective distress levels, which may remain high even with increased information and support; it is important to evaluate this.

Findings from other areas of behavioural medicine lead to the prediction that improved psychosocial services are cost-effective. Further research into the identification of patients who are at high risk and into the ability of psychosocial variables to predict pregnancy would permit a better evaluation of the costs and benefits of various program changes.

A clear definition of what role demands the gynaecologist can meet in the increasingly complex situation in the fertility clinic could permit planning for better resident training programs. For example, which psychosocial demands should the gynaecologist attempt to fulfill and which should be referred to the mental health professional require a clear policy decision that could affect medical school curricula.

Finally, continued sound longitudinal research on the evolution of psychosocial responses of fertility clinic patients is urgently needed, as there are many unanswered questions.

Table 1. Participation and Drop-Out Rates (n)

Duration of participation	Completed psychosocial battery and medical investigation for treatment	Did not complete psychosocial questionnaire: withdrew from medical investigation/treatment					Total non-participants from previous test
		Divorce	Pregnancy	Changed clinic	Completed telephone follow-up	Completed telephone follow-up after withdrawal from treatment reached	
Intake	686*	0	0	0	0	0	0
6 months	408	2	16	9	90	5	278
12 months	277	1	8	3	26	4	131
18 months	202	1	3	2	13	3	75
24 months	174	2	2	3	9	2	28
TOTAL		6	29	17	138	14	512

* A total of 16 cases were in medical investigation/treatment but refused to complete the psychosocial test battery at the following times: Intake = 2; 6 months = 5; 12 months = 4; 18 months = 3; and 24 months = 2.

Table 2. Psychosocial Data for No Treatment, Medication, Surgery, AID, IVF, and AIH at Five Times, by Gender (n*)

	Total sample			No treatment			Medication		
	Mean	SD	n	Mean	SD	n	Mean	SD	n
Marital adjustment (female)									
Intake	120.5	13.8	686				119.9	12.6	136
6 months	119.6	13.8	392	118.9	14.1	166	120.7	15.3	92
12 months	119.8	14.1	266	118.4	13.4	90	119.5	16.2	73
18 months	118.2	14.8	201	114.3	14.5	44	116.2	16.5	63
24 months	116.9	14.8	171	112.8	14.6	39	105.3	7.5	3
Q.-exp.**	116.9	14.8	98	0.0	0.0	0			
IVF									
Surgery									
	Mean	SD	n	Mean	SD	n	Mean	SD	n
6 months	122.7	15.5	29	121.4	11.5	19	118.5	10.7	22
12 months	122.5	12.6	24	119.5	13.1	21	120.7	11.4	20
18 months	121.0	10.3	23	120.8	12.4	18	117.8	10.4	20
24 months	122.6	9.1	17	121.5	14.7	15	119.3	10.2	19
Q.-exp.	0.0	0.0	0	111.1	14.2	20	118.2	15.0	48
AIH									
	Mean	SD	n						
6 months	118.4	20.2	20						
12 months	118.1	17.8	19						
18 months	117.3	18.6	23						
24 months	116.2	16.0	18						
Q.-exp.	119.2	15.0	21						

Table 2. (cont'd)

	Total sample			No treatment			Medication		
	Mean	SD	n	Mean	SD	n	Mean	SD	n
Marital adjustment (male)									
Intake	120.6	13.2	685						
6 months	119.9	13.2	392	119.2	13.0	166	120.8	12.9	136
12 months	120.1	13.9	266	120.1	13.7	90	120.5	13.2	92
18 months	118.9	14.0	199	117.3	15.4	44	119.8	13.6	73
24 months	117.9	14.8	169	117.9	13.0	39	117.2	16.5	62
Q.-exp.	118.4	14.3	80	0.0	0.0	0	115.0	13.1	3
Surgery			AID			IVF			
Mean	SD	n	Mean	SD	n	Mean	SD	SD	n
6 months	120.6	14.2	29	122.0	15.0	19	121.5	12.7	22
12 months	117.0	17.7	24	124.0	12.8	21	119.7	15.8	20
18 months	117.6	16.6	22	122.2	11.1	18	116.4	12.6	19
24 months	113.9	15.8	17	124.5	13.6	15	118.7	13.4	18
Q.-exp.	0.0	0.0	0	111.4	14.5	18	119.5	14.7	36
AIH									
Mean	SD	n							
6 months	116.1	13.8	20						
12 months	117.6	13.2	19						
18 months	119.8	13.4	23						
24 months	117.4	13.9	18						
Q.-exp.	122.5	13.5	17						

Table 2. (cont'd)

	Total sample			No treatment			Medication		
	Mean	SD	n	Mean	SD	n	Mean	SD	n
Sexual satisfaction (female)									
Intake	15.7	12.9	686						
6 months	17.0	14.0	392	17.3	13.6	166	17.6	14.8	136
12 months	17.2	14.3	267	17.7	14.4	90	17.7	15.3	93
18 months	18.4	14.6	200	20.6	15.0	43	18.3	15.8	73
24 months	18.5	15.9	171	18.7	15.6	39	20.5	17.8	63
Q.-exp.	23.0	15.0	96	0.0	0.0	0	34.3	10.1	3
Surgery									
	Mean	SD	n	Mean	SD	n	Mean	SD	n
AID									
6 months	11.3	10.4	29	19.1	12.5	19	17.0	14.0	22
12 months	12.7	9.4	24	18.8	12.7	21	16.0	15.8	20
18 months	14.8	10.9	23	19.8	13.8	18	15.4	13.0	20
24 months	15.4	12.6	17	17.0	15.3	15	13.7	13.3	19
Q.-exp.	0.0	0.0	0	25.7	13.0	20	21.1	16.2	46
IVF									
AIH									
	Mean	SD	n						
6 months	17.7	16.2	20						
12 months	17.9	14.2	19						
18 months	20.2	15.7	23						
24 months	20.3	15.4	18						
Q.-exp.	23.0	15.9	21						

Table 2. (cont'd)

	Total sample			No treatment			Medication		
	Mean	SD	n	Mean	SD	n	Mean	SD	n
Sexual satisfaction (male)									
Intake	16.5	12.7	685						
6 months	17.6	13.8	392	18.6	14.0	166	17.3	14.0	136
12 months	17.2	13.7	266	18.4	13.6	90	17.0	14.6	93
18 months	19.2	15.0	198	22.6	16.7	44	19.3	15.3	73
24 months	19.9	16.0	170	18.7	13.7	39	21.4	17.3	63
Q.-exp.	21.8	15.9	82	0.0	0.0	0	28.0	10.8	3
Surgery									
	Mean	SD	n	Mean	SD	n	Mean	SD	n
6 months	13.6	9.5	29	20.7	12.8	19	15.7	14.4	22
12 months	13.6	11.6	24	19.5	12.8	21	16.7	14.5	20
18 months	18.7	13.0	22	21.2	13.9	17	15.4	10.4	19
24 months	18.4	13.3	17	20.4	18.3	15	16.5	16.1	18
Q.-exp.	0.0	0.0	0	26.4	18.5	18	21.8	15.2	37
AIH									
	Mean	SD	n						
6 months	15.5	15.8	20						
12 months	14.7	12.3	18						
18 months	15.0	16.0	23						
24 months	21.4	17.5	18						
Q.-exp.	18.4	16.6	18						
IVF									
	Mean	SD	n	Mean	SD	n	Mean	SD	n
6 months	13.6	9.5	29	20.7	12.8	19	15.7	14.4	22
12 months	13.6	11.6	24	19.5	12.8	21	16.7	14.5	20
18 months	18.7	13.0	22	21.2	13.9	17	15.4	10.4	19
24 months	18.4	13.3	17	20.4	18.3	15	16.5	16.1	18
Q.-exp.	0.0	0.0	0	26.4	18.5	18	21.8	15.2	37

Table 2. (cont'd)

	Total sample			No treatment			Medication		
	Mean	SD	n	Mean	SD	n	Mean	SD	n
Self-esteem (female)									
Intake	16.1	4.4	682						
6 months	16.2	4.6	392	15.8	4.3	166	16.4	4.6	136
12 months	16.3	4.9	267	15.4	4.7	90	16.9	4.9	93
18 months	16.5	4.8	199	16.0	4.1	44	16.2	4.9	72
24 months	15.9	4.9	170	15.2	4.1	39	16.1	5.1	63
Q.-exp.	15.7	4.2	98	0.0	0.0	0	17.3	4.0	3
IVF									
Surgery									
	Mean	SD	n	Mean	SD	n	Mean	SD	n
6 months	15.9	3.9	29	15.3	4.4	19	17.0	4.2	22
12 months	15.7	4.0	24	16.5	4.3	21	16.5	5.0	20
18 months	17.0	5.2	22	16.4	3.8	18	15.6	3.8	20
24 months	15.1	4.0	17	15.2	4.1	15	14.7	3.5	19
Q.-exp.	0.0	0.0	0	15.8	4.1	20	15.9	4.6	48
AIH									
	Mean	SD	n						
6 months	18.3	6.7	20						
12 months	17.4	6.3	19						
18 months	18.6	6.2	23						
24 months	19.2	7.2	17						
Q.-exp.	15.2	3.7	21						

Table 2. (cont'd)

	Total sample			No treatment			Medication		
	Mean	SD	n	Mean	SD	n	Mean	SD	n
Self-esteem (male)									
Intake	14.8	3.9	681						
6 months	14.5	3.9	391	14.8	4.1	166	14.2	3.6	135
12 months	14.8	4.0	266	14.4	4.0	89	14.8	4.2	93
18 months	14.6	3.7	198	15.1	4.4	44	14.0	3.1	73
24 months	14.7	3.9	169	14.5	4.0	39	14.1	3.5	62
Q.-exp.	13.8	3.4	81	0.0	0.0	0	12.5	3.5	2
IVF									
Surgery									
	Mean	SD	n	Mean	SD	n	Mean	SD	n
6 months	14.2	3.8	29	14.0	3.9	19	14.6	4.3	22
12 months	15.1	4.1	24	15.1	4.0	21	16.0	4.5	20
18 months	15.2	3.7	21	15.3	3.7	18	14.9	3.7	19
24 months	16.4	4.6	17	14.9	4.0	15	14.7	3.3	18
Q.-exp.	0.0	0.0	0	14.3	3.2	18	13.7	3.9	38
AIH									
	Mean	SD	n						
6 months	14.9	3.9	20						
12 months	14.9	3.1	19						
18 months	14.2	4.3	23						
24 months	15.4	4.4	18						
Q.-exp.	14.2	3.2	17						

Table 2. (cont'd)

	Total sample			No treatment			Medication		
	Mean	SD	n	Mean	SD	n	Mean	SD	n
Psychiatric symptoms (female)									
Intake	19.7	12.3	686						
6 months	20.3	14.1	391	20.4	14.2	166	20.3	13.9	135
12 months	21.6	14.5	267	20.7	14.2	90	20.9	13.6	93
18 months	20.3	13.1	201	21.1	12.8	44	20.9	13.9	73
24 months	19.7	13.3	170	18.8	12.3	39	22.2	14.5	62
Q.-exp.	19.6	11.2	98	0.0	0.0	0	26.4	8.7	3
Surgery				AID			IVF		
	Mean	SD	n	Mean	SD	n	Mean	SD	n
6 months	17.6	13.0	29	18.6	11.7	19	20.2	14.2	22
12 months	24.5	12.7	24	24.0	17.8	21	23.5	13.9	20
18 months	18.8	12.7	23	18.4	13.4	18	18.7	8.9	20
24 months	13.3	9.7	17	16.6	11.0	15	16.8	8.2	19
Q.-exp.	0.0	0.0	0	17.8	11.8	20	20.5	9.9	48
AIH									
	Mean	SD	n						
6 months	25.3	18.1	20						
12 months	21.2	18.7	19						
18 months	21.5	15.5	23						
24 months	25.0	16.9	18						
Q.-exp.	17.8	11.1	21						

Table 2. (cont'd)

	Total sample			No treatment			Medication		
	Mean	SD	n	Mean	SD	n	Mean	SD	n
Psychological stress (female)									
Intake	68.2	28.0	684						
6 months	68.3	30.5	391	67.7	30.1	166	70.1	31.5	135
12 months	70.0	31.4	269	70.0	32.3	90	67.8	30.1	93
18 months	67.0	27.9	201	69.4	26.5	44	66.7	29.8	73
24 months	66.8	31.4	170	68.2	34.3	38	68.9	32.3	64
Q.-exp.	65.6	25.1	97	0.0	0.0	0	94.3	20.8	3
Surgery				AID			IVF		
	Mean	SD	n	Mean	SD	n	Mean	SD	n
6 months	64.6	28.7	29	66.8	22.7	19	59.5	28.5	22
12 months	72.3	25.3	23	74.2	35.6	21	75.3	31.4	23
18 months	66.3	25.2	23	66.4	31.3	18	60.9	23.5	20
24 months	54.0	19.4	17	63.1	29.8	15	59.7	24.7	18
Q.-exp.	0.0	0.0	0	67.0	25.4	20	63.2	20.9	47
AIH									
	Mean	SD	n						
6 months	77.3	37.1	20						
12 months	66.7	37.2	19						
18 months	69.6	29.5	23						
24 months	79.0	35.6	18						
Q.-exp.	62.9	27.7	21						

Table 2. (cont'd)

	Total sample			No treatment			Medication		
	Mean	SD	n	Mean	SD	n	Mean	SD	n
Psychological stress (male)									
Intake	63.0	25.3	680						
6 months	63.1	25.8	391	62.3	25.5	166	63.0	26.0	135
12 months	62.7	28.2	269	63.0	28.3	89	61.4	26.6	93
18 months	62.1	23.6	197	59.4	24.1	43	64.3	23.9	72
24 months	61.7	28.8	170	63.6	38.8	39	60.4	21.4	63
Q.-exp.	62.9	25.7	79	0.0	0.0	0	56.0	18.7	3
Surgery				AID			IVF		
	Mean	SD	n	Mean	SD	n	Mean	SD	n
6 months	59.1	25.3	29	66.9	30.4	19	66.0	24.3	22
12 months	59.2	30.2	24	62.9	30.1	21	72.7	32.2	23
18 months	57.5	18.1	22	61.6	24.3	18	64.8	23.9	19
24 months	60.5	24.0	17	56.2	24.1	15	66.3	31.4	18
Q.-exp.	0.0	0.0	0	75.6	36.8	18	62.5	20.7	35
AIH									
	Mean	SD	n						
6 months	68.5	26.9	20						
12 months	60.3	26.0	19						
18 months	63.0	27.1	23						
24 months	63.1	34.2	18						
Q.-exp.	56.8	20.6	17						

* n's in specific columns can be smaller than total because of subject failure to fill out one specific questionnaire.
** Q.-exp. = Quasi-experimental design group.

Table 3. Impression Management and Self-Deception as Measured by the Social Desirability Scale

		Intake*			6 months			12 months			18 months			24 months		
		Mean	SD	n	Mean	SD	n	Mean	SD	n	Mean	SD	n	Mean	SD	n
Impression management (men)		8.8	3.6	686												
No treatment				166	8.3	3.7		7.7	3.5	90	7.7	3.3	44	7.4	3.6	39
Medication				136	8.4	3.9		8.1	3.6	93	8.3	4.1	73	8.0	4.2	63
Surgery				29	7.9	3.7		7.5	3.3	24	7.3	3.3	22	6.1	3.3	17
AID				19	9.1	3.7		8.8	4.5	21	8.6	3.8	18	8.9	4.5	15
IVF				22	8.9	3.9		8.5	4.3	20	7.6	4.3	14	8.6	4.6	13
AIH				20	8.4	3.1		8.4	3.2	19	8.3	3.2	23	7.2	3.4	18
Self-deception (men)		10.6	3.2	683												
No treatment				165	10.4	3.3		9.8	3.2	89	9.8	3.0	44	9.7	3.3	39
Medication				136	10.4	3.1		10.9	3.4	92	10.9	3.5	73	10.6	3.6	63
Surgery				29	10.4	3.1		9.7	3.1	24	8.4	3.2	22	7.6	3.9	17
AID				19	9.6	3.4		9.6	4.3	21	9.6	3.7	18	10.4	4.4	15
IVF				22	11.1	2.8		10.0	2.8	20	10.3	2.8	14	10.5	3.0	13
AIH				20	10.0	3.3		10.4	3.0	19	9.9	3.8	21	9.7	3.9	18

Table 3. (cont'd)

		Intake*			6 months			12 months			18 months			24 months		
		Mean	SD	n	Mean	SD	n	Mean	SD	n	Mean	SD	n	Mean	SD	n
Impression management (women)		9.6	3.5	686												
No treatment					8.8	3.7	166	8.4	3.9	90	7.5	3.5	44	6.9	3.1	38
Medication					8.8	3.6	136	8.5	3.3	93	8.7	3.4	73	8.1	3.4	63
Surgery					8.3	3.6	29	8.3	3.4	24	8.5	4.2	23	6.4	3.0	17
AID					9.3	4.1	19	9.3	3.7	21	9.1	3.7	18	8.9	4.0	15
IVF					10.1	4.0	22	9.3	3.6	20	9.2	4.3	14	9.0	4.0	13
AIH					9.8	3.0	20	9.9	2.9	19	9.1	4.2	23	9.7	3.8	18
Self-deception (women)		10.4	3.1	683												
No treatment					9.8	3.5	166	9.9	2.9	90	9.0	3.0	44	9.2	3.3	39
Medication					10.1	2.9	136	10.0	3.1	93	10.1	3.2	73	9.7	2.9	63
Surgery					9.4	2.4	29	9.3	2.8	24	9.7	2.0	23	8.8	3.1	17
AID					9.9	3.6	19	9.3	2.7	21	9.2	2.6	18	10.1	3.4	15
IVF					10.1	3.2	22	10.3	3.3	20	10.0	3.9	14	9.2	3.9	13
AIH					9.9	3.0	20	9.8	3.8	19	10.3	3.3	23	10.0	3.2	18

* Intake refers to average score of total sample at intake.

Table 4A. Summary of Psychosocial Response of Male and Female Patients at Intake

Name of dependent measure	First author of English/French version of instrument	Female		Male		Probability of two-tailed t-test infertility (women versus men)
		Mean	SD	Mean	SD	
Index of psychiatric symptomatology						
Total score	Illfeld/Kovess	19.72	12.42	16.43	10.72	p < 0.0001
Depression subscale	Illfeld/Kovess	19.03	13.80	13.75	10.94	p < 0.0001
Anxiety subscale	Illfeld/Kovess	17.87	13.33	15.19	11.90	p = 0.001
Cognitive difficulties subscale	Illfeld/Kovess	19.07	15.97	17.31	14.99	p < 0.05
Hostility subscale	Illfeld/Kovess	26.87	18.31	24.45	15.69	p < 0.025
Self-esteem	Rosenberg/Vallières	16.27	4.45	14.78	3.72	p < 0.0001
Psychosocial state of stress	Lemyre	68.15	27.56	64.00	25.03	p < 0.007
Dyadic adjustment scale	Spanier/Baillargeon	121.82	14.34	122.02	13.57	p = 0.753
Sexual satisfaction	Hudson/Comeau	16.31	12.86	17.19	12.90	p = 0.130
Inventory of socially desirable responding						
Impression management	Paulhus/Sabourin	96.70	14.69	93.14	14.67	p < 0.0001
Self-deception	Paulhus/Sabourin	100.34	13.04	102.15	12.37	p = 0.803

Table 4B. Contrast Between Infertile Patients and Population Norms on Psychiatric Symptoms at Intake

Index of psychiatric symptomatology	Women						Men					
	Infertile			Normal			Infertile			Normal		
	Mean	SD	%	Mean	SD	%	Mean	SD	%	Mean	SD	%
Total score	19.72	12.42 ^a	25.0	15.95	13.15	18.6	16.40	10.72 ^a	17.0	12.39	11.49	11.4
Depression subscale	19.03	13.80 ^b	23.2	17.62	15.54	19.8	13.75	10.94 ^b	9.8	12.18	12.89	10.2
Anxiety subscale	17.81	13.33 ^a	24.3	14.24	13.36	18.0	15.19	11.90 ^a	20.1	11.53	11.82	12.0
Cognitive difficulties subscale	19.07	15.97 ^a	22.9	14.51	16.02	16.7	17.31	14.99 ^a	20.5	12.53	14.87	13.3
Hostility subscale	26.87	18.31 ^a	31.1	17.92	17.41	16.8	24.45	15.69 ^a	27.7	15.14	16.44	13.2

^a t-test of infertile patients versus same-sexed normals, p < 0.0001

^b t-test of infertile patients versus same-sexed normals, p < 0.05

Table 5. Psychosocial Data for No Treatment, Medication, Surgery, AID, IVF, and AIH, by Pregnancy Status for Women and Their Partners

	Marital adjustment (female)					Marital adjustment (male)				
	6 mo	12 mo	18 mo	24 mo	Q-exp	6 mo	12 mo	18 mo	24 mo	Q-exp
No treatment										
No pregnancy										
Mean	118.4	117.6	112.6	109.9	0.0	118.3	119.9	113.0	115.5	0.0
SD	14.7	14.0	12.6	18.5	0.0	13.1	14.6	12.5	13.5	0.0
n	137	62	23	15	0	137	62	23	15	0
Pregnancy										
Mean	120.8	120.0	115.8	114.8	0.0	122.4	120.5	120.7	118.7	0.0
SD	11.3	12.2	17.1	11.9	0.0	12.4	11.6	17.2	12.5	0.0
n	27	28	19	23	0	27	28	19	23	0
Ectopic										
Mean	126.0	0.0	119.0	112.0	0.0	132.0	0.0	135.5	135.0	0.0
SD	0.0	0.0	9.9	0.0	0.0	7.1	0.0	9.2	0.0	0.0
n	2	0	2	1	0	2	0	2	1	0
Medication										
No pregnancy										
Mean	119.3	119.3	117.0	113.8	101.5	120.0	120.9	120.0	118.8	116.0
SD	13.2	16.7	16.7	15.9	5.0	13.2	13.9	14.0	15.2	18.4
n	106	59	36	25	2	106	60	36	25	2
Pregnancy										
Mean	123.1	122.4	122.5	117.6	113.0	121.6	118.9	119.5	115.4	113.0
SD	9.2	11.9	14.0	17.1	0.0	12.7	11.9	13.5	17.7	0.0
n	20	29	32	36	1	20	29	32	35	1

Table 5. (cont'd)

	Marital adjustment (female)					Marital adjustment (male)				
	6 mo	12 mo	18 mo	24 mo	Q-exp	6 mo	12 mo	18 mo	24 mo	Q-exp
Ectopic										
Mean	120.6	129.0	118.8	120.5	0.0	126.7	128.7	120.8	128.5	0.0
SD	12.1	14.3	25.8	14.8	0.0	6.8	9.6	13.0	0.7	0.0
n	10	4	5	2	0	10	3	5	2	0
Surgery										
No pregnancy										
Mean	122.2	122.8	121.8	125.6	0.0	119.6	117.2	119.9	118.7	0.0
SD	15.9	12.6	11.0	8.3	0.0	14.0	17.5	17.0	15.8	0.0
n	25	20	14	9	0	25	20	14	9	0
Pregnancy										
Mean	125.5	121.0	117.7	121.0	0.0	126.8	116.5	111.4	110.2	0.0
SD	14.2	14.6	7.8	11.3	0.0	16.5	21.7	15.0	18.8	0.0
n	4	4	6	5	0	4	4	5	5	0
Ectopic										
Mean	0.0	0.0	124.0	116.3	0.0	0.0	0.0	117.7	105.7	0.0
SD	0.0	0.0	13.0	5.7	0.0	0.0	0.0	21.0	7.4	0.0
n	0	0	3	3	0	0	0	3	3	0
AID										
No pregnancy										
Mean	120.8	117.4	118.7	120.8	112.5	121.5	123.6	121.3	127.3	115.9
SD	12.3	12.9	12.3	16.4	10.7	16.0	13.4	12.2	12.7	9.2
n	16	17	12	10	13	16	17	12	10	12
Pregnancy										
Mean	124.7	128.5	125.2	123.0	103.8	124.7	126.0	124.2	119.0	96.8
SD	5.9	11.4	12.7	12.1	17.2	9.3	10.8	9.0	15.0	15.5
n	3	4	6	5	6	3	4	6	5	5

[illegible]

Table 5. (cont'd)

	Sexual satisfaction (female)					Sexual satisfaction (male)				
	6 mo	12 mo	18 mo	24 mo	Q-exp	6 mo	12 mo	18 mo	24 mo	Q-exp
No treatment										
No pregnancy	17.7	19.6	24.4	27.5	0.0	18.6	18.5	26.4	23.5	0.0
	13.7	15.5	13.0	16.4	0.0	14.2	14.1	15.3	15.1	0.0
	13.7	62	23	15	0	137	62	23	15	0
Pregnancy	16.0	13.6	16.8	12.9	0.0	19.3	18.1	18.1	15.3	0.0
	13.4	10.9	16.7	12.8	0.0	13.0	12.5	18.0	12.2	0.0
	27	28	18	23	0	27	28	19	23	0
Ectopic	6.0	0.0	10.0	22.0	0.0	8.5	0.0	21.5	25.0	0.0
	4.2	0.0	11.3	0.0	0.0	6.4	0.0	16.3	0.0	0.0
	2	0	2	1	0	2	0	2	1	0
Medication										
No pregnancy	17.7	19.2	20.8	24.2	37.5	17.0	17.0	20.8	23.9	29.5
	15.5	16.3	16.6	17.8	12.0	14.5	14.9	16.4	16.9	14.9
	106	60	36	25	2	106	60	36	25	2
Pregnancy	14.3	13.9	14.6	18.4	28.0	18.4	17.5	18.3	20.7	25.0
	11.0	11.9	14.1	17.9	0.0	13.1	14.7	14.7	17.6	0.0
	20	29	32	36	1	20	29	32	36	1
Ectopic	22.7	22.8	23.0	12.0	0.0	17.8	14.5	14.6	3.0	0.0
	14.0	19.1	18.0	17.0	0.0	11.7	13.0	10.8	0.0	0.0
	10	4	5	2	0	10	4	5	2	0

surgery

No pregnancy
Mean
SD
n

12.2	12.1	14.1	12.1	0.0	13.7	13.1	16.9	12.6	0.0
10.8	9.3	12.9	13.8	0.0	9.1	11.8	13.4	10.8	0.0
25	20	14	9	0	25	20	14	9	0

Pregnancy
Mean
SD
n

5.3	15.8	16.8	20.6	0.0	13.0	16.0	23.2	23.4	0.0
3.8	10.7	6.2	13.4	0.0	13.5	11.9	11.5	13.8	0.0
4	4	6	5	0	4	4	5	5	0

Ectopic
Mean
SD
n

0.0	0.0	13.7	16.7	0.0	0.0	0.0	19.7	27.3	0.0
0.0	0.0	10.6	6.4	0.0	0.0	0.0	16.6	15.1	0.0
0	0	3	3	0	0	0	3	3	0

AID

No pregnancy
Mean
SD
n

20.2	20.4	22.6	19.3	22.9	22.3	21.4	25.0	24.0	20.1
12.5	13.6	15.6	18.2	13.0	13.3	13.2	14.8	20.8	13.0
16	17	12	10	13	16	17	12	10	12

Pregnancy
Mean
SD
n

13.0	12.0	14.2	12.4	29.5	12.3	11.8	12.0	13.2	38.4
13.1	3.9	7.5	5.9	13.3	6.1	8.1	5.1	9.9	24.8
3	4	6	5	6	3	4	5	5	5

Ectopic
Mean
SD
n

0.0	0.0	0.0	0.0	38.0	0.0	0.0	0.0	0.0	43.0
0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
0	0	0	0	1	0	0	0	0	1

IVF

No pregnancy
Mean
SD
n

13.3	11.6	15.9	15.3	23.9	13.3	15.7	15.3	16.0	24.5
10.2	8.4	11.8	14.8	17.9	13.4	15.0	10.2	14.9	16.5
19	13	14	12	31	19	13	13	11	24

Table 5. (cont'd)

	Sexual satisfaction (female)					Sexual satisfaction (male)				
	6 mo	12 mo	18 mo	24 mo	Q-exp	6 mo	12 mo	18 mo	24 mo	Q-exp
Pregnancy										
Mean	40.3	21.3	17.0	11.1	15.4	31.0	14.5	18.6	17.3	17.9
SD	13.7	24.1	16.9	10.9	10.7	12.5	10.8	10.1	18.9	11.4
n	3	6	5	7	13	3	6	5	7	11
Ectopic										
Mean	0.0	40.0	0.0	0.0	15.5	0.0	42.0	0.0	0.0	10.5
SD	0.0	0.0	0.0	0.0	7.8	0.0	0.0	0.0	0.0	12.0
n	0	1	1	0	2	0	1	1	0	2
AIH										
No pregnancy										
Mean	14.3	17.9	17.1	19.2	19.8	13.8	14.7	12.4	16.8	17.2
SD	14.0	15.1	14.8	17.0	13.1	14.8	13.0	13.1	16.2	16.6
n	17	17	18	13	16	17	16	18	13	14
Pregnancy										
Mean	37.0	18.5	31.2	23.2	34.3	25.0	15.0	24.0	33.4	22.7
SD	16.5	2.1	15.1	11.3	24.1	21.5	5.7	23.3	16.4	22.7
n	3	2	5	5	4	3	2	5	5	3
Ectopic										
Mean	0.0	0.0	0.0	0.0	29.0	0.0	0.0	0.0	0.0	23.0
SD	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
n	0	0	0	0	1	0	0	0	0	1
Self-esteem (female)										
Self-esteem (male)										
No treatment										
No pregnancy										
Mean	15.8	15.8	16.7	16.5	0.0	14.8	14.4	15.1	14.7	0.0
SD	4.5	5.1	4.5	4.8	0.0	4.1	3.9	3.5	4.0	0.0

Mean	16.5	14.6	15.6	14.2	0.0	14.6	14.4	15.5	14.5	0.0
SD	3.6	3.6	3.4	3.3	0.0	4.1	4.2	5.3	4.1	0.0
n	27	28	19	23	0	27	27	19	23	0
Ectopic										
Mean	13.0	0.0	13.0	18.0	0.0	13.0	0.0	10.5	10.0	0.0
SD	4.2	0.0	4.2	0.0	0.0	1.4	0.0	0.7	0.0	0.0
n	2	0	2	1	0	2	0	2	1	0
Medication										
No pregnancy										
Mean	16.6	17.3	17.2	17.5	15.5	14.4	14.8	13.8	13.5	12.5
SD	4.8	4.9	4.8	5.6	3.5	3.8	4.4	2.8	3.1	3.5
n	106	60	36	26	2	105	60	36	26	2
Pregnancy										
Mean	15.3	16.0	15.3	14.9	21.0	13.5	14.8	14.3	14.5	0.0
SD	3.0	4.1	5.0	4.5	0.0	2.6	3.8	3.5	3.8	0.0
n	20	29	31	36	1	20	29	32	35	0
Ectopic										
Mean	16.6	18.5	14.4	17.5	0.0	13.4	15.3	13.4	13.0	0.0
SD	5.0	9.3	3.8	5.0	0.0	3.0	3.5	2.2	4.2	0.0
n	10	4	5	2	0	10	4	5	2	0
Surgery										
No pregnancy										
Mean	16.4	15.1	17.4	14.0	0.0	14.2	14.7	14.5	16.0	0.0
SD	3.9	4.1	5.6	4.4	0.0	3.8	3.3	3.6	5.3	0.0
n	25	20	14	9	0	25	20	13	9	0
Pregnancy										
Mean	13.0	18.8	17.0	16.2	0.0	14.3	17.5	16.4	17.0	0.0
SD	2.6	1.7	3.2	3.6	0.0	4.6	7.4	2.7	3.8	0.0
n	4	4	5	5	0	4	4	5	5	0
Ectopic										
Mean	0.0	0.0	15.7	16.3	0.0	0.0	0.0	16.0	16.3	0.0
SD	0.0	0.0	7.4	3.5	0.0	0.0	0.0	6.0	4.9	0.0
n	0	0	3	3	0	0	0	3	3	0

No pregnancy	Mean	18.2	17.2	18.1	19.5	15.7	14.2	14.7	13.1	14.8	14.6
	SD	6.8	6.4	6.3	7.6	3.5	3.7	3.1	3.8	4.1	3.3
	n	17	17	18	12	16	17	17	18	13	13
Pregnancy	Mean	18.7	19.0	20.4	18.6	14.3	18.7	17.0	18.4	17.0	12.3
	SD	7.8	7.1	6.2	6.8	4.9	2.5	2.8	3.6	5.4	3.2
	n	3	2	5	5	4	3	2	5	5	3
Ectopic	Mean	0.0	0.0	0.0	0.0	12.0	0.0	0.0	0.0	0.0	15.0
	SD	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
	n	0	0	0	0	1	0	0	0	0	1
Psychiatric symptoms (female)											
Psychiatric symptoms (male)											
No treatment	Mean	20.7	22.4	22.1	21.7	0.0	15.6	16.9	19.0	19.5	0.0
	SD	14.8	16.0	14.0	14.7	0.0	12.1	12.0	12.2	17.6	0.0
	n	137	62	23	15	0	136	62	23	15	0
Pregnancy	Mean	19.7	17.1	21.1	16.9	0.0	13.3	14.4	12.3	15.4	0.0
	SD	11.2	8.5	11.7	10.7	0.0	7.3	9.0	8.3	15.5	0.0
	n	27	28	19	23	0	27	28	19	23	0
Ectopic	Mean	8.0	0.0	10.9	18.4	0.0	10.9	0.0	10.3	10.3	0.0
	SD	3.3	0.0	4.1	0.0	0.0	2.4	0.0	3.3	0.0	0.0
	n	2	0	2	1	0	2	0	2	1	0
Medication											
No pregnancy	Mean	21.0	22.2	21.0	24.4	22.4	16.3	14.9	14.8	14.1	15.5
	SD	14.6	13.8	11.5	11.2	7.3	11.9	11.8	9.2	7.3	5.7
	n	106	60	36	24	2	106	60	36	25	2

Table 5. (cont'd)

	Psychiatric symptoms (female)					Psychiatric symptoms (male)				
	6 mo	12 mo	18 mo	24 mo	Q-exp	6 mo	12 mo	18 mo	24 mo	Q-exp
Pregnancy										
Mean	18.0	18.4	20.7	20.9	34.5	17.8	17.9	18.6	16.8	12.6
SD	9.6	10.8	16.6	16.6	0.0	12.6	12.5	12.4	11.9	0.0
n	19	29	32	36	1	20	29	31	35	1
Ectopic										
Mean	17.7	20.1	21.6	20.1	0.0	15.2	15.2	12.4	12.6	0.0
SD	12.4	26.9	13.7	5.7	0.0	15.7	19.3	7.5	8.1	0.0
n	10	4	5	2	0	10	4	5	2	0
Surgery										
No pregnancy										
Mean	19.4	25.8	22.3	14.9	0.0	16.5	17.8	14.1	16.6	0.0
SD	13.2	13.4	14.4	12.0	0.0	12.4	14.7	11.6	13.4	0.0
n	25	20	14	9	0	25	20	14	9	0
Pregnancy										
Mean	6.9	17.8	13.2	9.7	0.0	6.6	8.9	14.3	17.2	0.0
SD	3.6	6.4	5.8	7.9	0.0	4.4	9.0	8.2	12.9	0.0
n	4	4	6	5	0	4	4	5	5	0
Ectopic										
Mean	0.0	0.0	13.4	14.6	0.0	0.0	0.0	16.1	14.6	0.0
SD	0.0	0.0	10.3	2.9	0.0	0.0	0.0	12.6	5.9	0.0
n	0	0	3	3	0	0	0	3	3	0
AID										
No pregnancy										
Mean	17.9	24.7	19.1	17.1	18.7	20.0	17.9	17.6	14.6	16.3
SD	12.4	19.5	12.7	12.2	13.8	12.5	13.5	9.0	9.8	11.5
n	16	17	12	10	13	16	17	12	10	12

Pregnancy	Mean	22.2	21.3	17.1	15.6	18.4	12.6	16.1	15.5	18.4	35.2
	SD	8.2	8.9	15.9	9.4	4.5	2.0	7.9	8.3	13.8	23.2
	n	3	4	6	5	6	3	4	6	5	5
Ectopic	Mean	0.0	0.0	0.0	0.0	1.2	0.0	0.0	0.0	0.0	25.3
	SD	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
	n	0	0	0	0	1	0	0	0	0	1
IVF											
No pregnancy	Mean	20.4	24.4	20.6	17.8	21.7	13.1	22.2	17.4	20.2	18.8
	SD	15.2	14.7	9.0	8.1	10.7	9.3	14.2	9.6	10.9	8.9
	n	19	13	14	12	32	19	13	13	10	24
Pregnancy	Mean	18.8	22.0	14.0	14.9	19.4	23.8	18.4	17.0	12.5	14.6
	SD	5.7	14.5	8.5	8.6	8.2	3.3	14.7	11.5	9.7	12.7
	n	3	6	5	7	13	3	6	5	7	11
Ectopic	Mean	0.0	20.7	14.9	0.0	13.4	0.0	27.6	5.7	0.0	10.3
	SD	0.0	0.0	0.0	0.0	5.2	0.0	0.0	0.0	0.0	8.1
	n	0	1	1	0	3	0	1	1	0	2
AIH											
No pregnancy	Mean	22.4	20.9	17.4	24.4	17.5	17.0	15.3	13.7	14.4	14.5
	SD	17.1	19.8	14.8	16.6	11.6	11.6	8.1	10.9	13.5	10.5
	n	17	17	18	13	16	17	17	18	13	13
Pregnancy	Mean	42.1	24.1	36.1	26.4	19.5	24.5	22.4	21.8	17.2	13.4
	SD	16.8	1.6	6.4	19.4	12.3	4.0	4.1	7.8	12.0	8.8
	n	3	2	5	5	4	3	2	5	5	3
Ectopic	Mean	0.0	0.0	0.0	0.0	16.1	0.0	0.0	0.0	0.0	1.2
	SD	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
	n	0	0	0	0	1	0	0	0	0	1

Table 5. (cont'd)		Psychological stress (female)					Psychological stress (male)				
		6 mo	12 mo	18 mo	24 mo	Q-exp	6 mo	12 mo	18 mo	24 mo	Q-exp
No treatment											
No pregnancy	Mean	69.1	73.3	74.8	75.6	0.0	63.1	65.4	61.7	77.2	0.0
	SD	31.2	34.4	26.9	35.8	0.0	26.7	30.0	26.1	50.2	0.0
	n	137	62	23	15	0	137	62	22	15	0
Pregnancy	Mean	63.1	62.9	65.5	63.1	0.0	59.3	57.4	57.3	54.9	0.0
	SD	23.2	26.2	25.3	34.0	0.0	19.3	23.6	23.3	28.1	0.0
	n	27	28	19	22	0	27	27	19	23	0
Ectopic	Mean	32.5	0.0	44.0	70.0	0.0	48.0	0.0	55.0	58.0	0.0
	SD	2.1	0.0	21.2	0.0	0.0	5.7	0.0	5.7	0.0	0.0
	n	2	0	2	1	0	2	0	2	1	0
Medication											
No pregnancy	Mean	73.3	73.2	69.1	76.3	86.0	63.5	58.1	60.5	57.2	47.5
	SD	32.7	32.8	26.5	28.7	21.2	26.6	26.1	22.5	18.0	16.3
	n	105	60	36	25	2	105	60	35	25	2
Pregnancy	Mean	57.7	57.3	62.8	64.9	111.0	62.4	70.8	70.6	64.2	73.0
	SD	21.8	19.4	30.0	34.9	0.0	23.8	25.9	25.0	23.4	0.0
	n	20	29	32	36	1	20	29	32	35	1
Ectopic	Mean	60.6	63.0	73.8	64.5	0.0	59.4	42.8	50.4	44.0	0.0
	SD	27.9	37.4	51.3	7.8	0.0	25.9	23.8	17.1	17.0	0.0
	n	10	4	5	2	0	10	4	5	2	0

Surgery

No pregnancy

Mean	67.2	77.7	74.9	53.4	0.0	62.2	61.8	54.8	54.4	0.0
SD	29.9	24.4	28.0	21.6	0.0	25.7	32.2	19.3	25.7	0.0
n	25	19	14	9	0	25	20	14	9	0

Pregnancy

Mean	48.8	46.5	55.5	50.6	0.0	39.5	46.3	61.8	62.2	0.0
SD	11.2	5.9	11.9	12.9	0.0	8.7	12.1	13.7	21.0	0.0
n	4	4	6	5	0	4	4	5	5	0

Ectopic

Mean	0.0	0.0	48.3	61.3	0.0	0.0	0.0	63.3	76.0	0.0
SD	0.0	0.0	13.8	26.6	0.0	0.0	0.0	22.0	23.9	0.0
n	0	0	3	3	0	0	0	3	3	0

AID

No pregnancy

Mean	65.8	78.4	72.6	68.4	69.5	69.8	65.7	63.7	50.9	60.8
SD	24.2	38.0	31.6	34.4	29.0	32.2	32.2	27.5	19.1	32.1
n	16	17	12	10	13	16	17	12	10	12

Pregnancy

Mean	72.0	56.5	54.2	52.4	65.5	52.0	51.0	57.5	66.8	107.6
SD	14.1	15.0	29.6	15.4	17.2	10.6	17.1	17.7	31.6	30.3
n	3	4	6	5	6	3	4	6	5	5

Ectopic

Mean	0.0	0.0	0.0	0.0	43.0	0.0	0.0	0.0	0.0	92.0
SD	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
n	0	0	0	0	1	0	0	0	0	1

IVF

No pregnancy

Mean	60.8	73.8	65.9	58.5	62.4	61.2	75.8	65.8	74.6	63.6
SD	30.4	23.6	25.5	20.7	18.7	21.4	35.7	24.9	35.1	19.6
n	19	13	14	11	31	19	13	13	11	23

Table 5. (cont'd)

	Psychological stress (female)					Psychological stress (male)				
	6 mo	12 mo	18 mo	24 mo	Q-exp	6 mo	12 mo	18 mo	24 mo	Q-exp
Pregnancy										
Mean	51.0	69.5	47.2	61.6	65.7	96.7	69.0	65.2	53.1	60.5
SD	8.9	38.4	13.5	31.7	28.1	22.1	35.6	25.6	20.2	24.6
n	3	6	5	7	13	3	6	5	7	11
Ectopic										
Mean	0.0	59.0	58.0	0.0	60.7	0.0	79.0	51.0	0.0	61.0
SD	0.0	0.0	0.0	0.0	4.5	0.0	0.0	0.0	0.0	0.0
n	0	1	1	0	3	0	1	1	0	1
AIH										
No pregnancy										
Mean	70.8	68.0	61.3	82.3	61.9	66.2	57.8	60.1	62.2	59.3
SD	35.9	39.3	26.6	36.6	28.3	27.7	25.7	29.4	39.4	22.4
n	17	17	18	13	16	17	17	18	13	13
Pregnancy										
Mean	114.3	56.0	99.4	70.4	70.8	81.3	82.0	73.8	65.4	48.7
SD	18.6	7.1	18.3	35.3	30.9	21.6	22.6	13.0	17.0	14.6
n	3	2	5	5	4	3	2	5	5	3
Ectopic										
Mean	0.0	0.0	0.0	0.0	47.0	0.0	0.0	0.0	0.0	49.0
SD	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
n	0	0	0	0	1	0	0	0	0	1
Intrusion (female)										
Intrusion (male)										
No treatment										
No pregnancy										
Mean	42.7	41.8	32.9	35.7	0.0	36.0	38.5	19.9	50.7	0.0
SD	21.1	24.5	14.5	16.4	0.0	20.6	24.1	3.8	30.9	0.0

Table 5. (cont'd)

	Intrusion (female)					Intrusion (male)				
	6 mo	12 mo	18 mo	24 mo	Q-exp	6 mo	12 mo	18 mo	24 mo	Q-exp
AID										
No pregnancy										
Mean	50.9	56.9	46.9	59.9	41.4	42.4	40.1	56.0	51.4	37.0
SD	21.4	25.3	23.3	33.8	20.6	27.8	23.4	35.9	34.8	24.5
n	16	15	9	7	8	15	15	10	7	8
Pregnancy										
Mean	37.7	35.0	33.5	60.0	51.0	36.0	45.0	34.0	74.0	53.5
SD	18.1	25.5	23.3	0.0	18.4	3.0	0.0	24.0	0.0	24.8
n	3	2	2	1	2	3	1	2	1	2
Ectopic										
Mean	0.0	0.0	0.0	0.0	19.0	0.0	0.0	0.0	0.0	17.0
SD	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
n	0	0	0	0	1	0	0	0	0	1
IVF										
No pregnancy										
Mean	78.3	77.6	57.0	58.5	64.6	55.9	54.6	59.8	53.8	52.9
SD	24.1	22.9	36.3	9.4	28.8	21.4	25.1	26.3	29.2	23.2
n	18	13	4	4	21	18	13	4	4	15
Pregnancy										
Mean	80.7	69.7	83.0	67.3	52.7	54.0	31.3	71.0	66.5	41.8
SD	9.5	29.6	0.0	21.0	23.7	8.7	13.2	3.0	36.1	24.8
n	3	3	1	3	6	3	3	1	2	6
Ectopic										
Mean	0.0	48.0	103.0	0.0	76.5	0.0	55.0	40.0	0.0	49.0
SD	0.0	0.0	0.0	0.0	13.4	0.0	0.0	0.0	0.0	0.0
n	0	1	1	0	2	0	1	1	0	1

AIH

No pregnancy	Mean	47.4	48.1	48.7	41.8	54.2	39.1	47.2	31.6	24.6	37.0
	SD	25.8	17.0	22.8	14.2	21.4	21.0	27.9	23.2	16.0	15.6
	n	17	15	14	8	6	17	15	13	8	5
Pregnancy	Mean	53.7	51.0	64.0	62.0	69.0	44.7	94.0	61.3	49.0	70.0
	SD	13.5	18.4	8.5	50.9	0.0	13.3	12.7	27.4	8.5	0.0
	n	3	2	2	2	1	3	2	3	2	1
Ectopic	Mean	0.0	0.0	0.0	0.0	44.0	0.0	0.0	0.0	0.0	41.0
	SD	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
	n	0	0	0	0	1	0	0	0	0	1

Table 6. Percentage of Patients Above Clinical Cut-Off Points

Total sample		No treatment		Medication		Surgery		AID		IVF		AIH		
n	%	n	%	n	%	n	%	n	%	n	%	n	%	
Psychiatric symptoms (male)														
Intake	130	19.0	31	18.7	28	20.6	4	13.8	4	21.1	2	9.1	4	20.0
6 months	80	19.7	30	18.2	28	20.6	7	24.1	5	26.3	4	18.2	4	20.0
12 months	61	22.1	19	21.1	18	19.4	6	25.0	7	33.3	8	40.0	3	15.8
18 months	37	18.5	7	15.9	15	20.8	4	18.2	2	11.1	3	21.4	5	21.7
24 months	36	20.8	10	25.6	11	17.7	2	11.8	3	20.0	4	30.8	4	22.2
Q.-exp.	16	19.8	0	0	0	0.0	0	0	5	27.8	8	21.6	3	17.6
Psychiatric symptoms (female)														
Intake	193	28.1	48	28.9	43	31.6	10	34.5	4	21.1	3	13.6	7	35.0
6 months	121	29.7	46	27.7	41	30.4	8	27.6	6	31.6	7	31.8	8	40.0
12 months	87	31.4	27	30.0	27	29.0	10	41.7	8	38.1	7	35.0	6	31.6
18 months	66	32.7	16	36.4	21	28.8	6	26.1	6	33.3	6	42.9	9	39.1
24 months	55	31.8	13	33.3	22	35.5	3	17.6	4	26.7	2	15.4	8	44.4
Q.-exp.	30	30.6	0	0	2	66.7	0	0	3	15.0	18	37.5	5	23.8
Psychiatric symptom index (PSI) anxiety (male)														
Intake	149	21.7	36	21.7	34	25.0	4	13.8	4	21.1	1	4.5	5	25.0
6 months	77	18.9	29	17.5	22	16.2	7	24.1	7	36.8	5	22.7	5	25.0
12 months	60	21.7	20	22.2	19	20.4	6	25.0	5	23.8	8	40.0	2	10.5
18 months	34	16.9	7	15.9	13	17.8	4	18.2	3	16.7	2	14.3	4	17.4
24 months	38	22.0	9	23.1	12	19.4	3	17.6	2	13.3	5	38.5	4	22.2
Q.-exp.	18	22.2	0	0	0	0.0	0	0	5	27.8	10	27.0	3	17.6
PSI anxiety (female)														
Intake	193	28.1	52	31.3	40	29.4	7	24.1	5	26.3	3	13.6	9	45.0
6 months	127	31.1	51	30.7	44	32.4	6	20.7	5	26.3	8	36.4	7	35.0
12 months	87	31.4	29	32.2	29	31.2	10	41.7	6	28.6	7	35.0	4	21.1
18 months	64	31.7	18	40.9	21	28.8	4	17.4	3	16.7	5	35.7	10	43.5
24 months	56	32.2	12	30.8	22	34.9	3	17.6	4	26.7	2	15.4	10	55.6
Q.-exp.	21	21.4	0	0	2	66.7	0	0	6	30.0	8	16.7	3	14.3

Intake	67	9.8	16	9.6	16	11.8	1	3.4	1	5.3	1	4.5	4	20.0
6 months	42	10.3	18	10.9	16	11.8	2	6.9	1	5.3	1	4.5	3	15.0
12 months	39	14.1	12	13.3	13	14.0	4	16.7	3	14.3	6	30.0	1	5.3
18 months	24	12.0	6	13.6	11	15.3	1	4.5	3	16.7	0	0.0	2	8.7
24 months	19	11.0	4	10.3	3	4.8	1	5.9	3	20.0	3	23.1	3	16.7
Q.-exp.	6	7.4	0	0	0	0	0	0	3	16.7	2	5.4	1	5.9

PSI depression (female)

Intake	151	22	31	18.7	34	25.0	8	27.6	3	15.8	1	4.5	7	35.0
6 months	95	23.3	36	21.7	30	22.2	6	20.7	5	26.3	6	27.3	8	40.0
12 months	77	27.8	26	28.9	23	24.7	9	35.7	5	23.8	7	35.0	5	26.3
18 months	54	26.7	14	31.8	15	20.5	5	21.7	5	27.8	4	28.6	9	39.1
24 months	37	21.4	12	30.8	15	24.2	1	5.9	0	0.0	1	7.7	6	33.3
Q.-exp.	30	30.7	0	0	2	66.7	0	0	4	20.0	17	35.4	5	23.8

PSI cognitive disturbance (male)

Intake	256	37.3	64	38.6	59	43.4	5	17.2	7	36.8	6	27.3	6	30.0
6 months	153	37.5	61	36.7	52	38.2	9	31.0	9	47.4	8	36.4	9	45.0
12 months	106	38.4	29	32.2	35	37.6	11	45.8	8	38.1	11	55.0	10	52.6
18 months	83	41.3	17	38.6	30	41.1	7	31.8	6	33.3	9	64.3	11	47.8
24 months	64	36.8	13	33.3	24	38.1	8	47.1	6	40.0	4	30.8	6	33.3
Q.-exp.	29	35.8	0	0	1	33.3	0	0	7	38.9	15	40.5	5	29.4

PSI cognitive disturbance (female)

Intake	278	40.5	71	42.8	58	42.6	13	44.8	3	15.8	5	22.7	10	50.0
6 months	160	39.2	72	43.4	50	36.8	8	27.6	6	31.6	9	40.9	9	45.0
12 months	121	43.7	34	37.8	41	44.1	15	62.5	7	33.3	9	0.0	11	57.9
18 months	82	40.6	18	40.9	32	43.8	6	26.1	6	33.3	7	50.0	10	43.5
24 months	68	39.1	15	38.5	29	46.0	4	23.5	4	26.7	1	7.7	9	50
Q.-exp.	41	41.8	0	0	1	33.3	0	0	6	30.0	23	47.9	9	42.9

PSI hostility (male)

Intake	390	56.9	92	55.4	84	61.8	14	48.3	9	47.4	9	40.9	12	60.0
6 months	220	53.9	82	49.4	77	56.6	17	58.6	12	63.2	11	50.0	13	65.0
12 months	157	56.9	49	54.4	51	54.8	13	54.2	14	66.7	13	65.0	14	73.7
18 months	119	59.2	24	54.5	48	65.8	11	50.0	12	66.7	8	57.1	12	52.2
24 months	101	58.4	22	56.4	38	61.3	11	64.7	9	60.0	9	69.2	9	50.0
Q.-exp.	51	63.0	0	0	2	66.7	0	0	13	72.2	26	70.3	6	35.3

Table 6. (cont'd)

Total sample		No treatment		Medication		Surgery		AID		IVF		AIH		
n	%	n	%	n	%	n	%	n	%	n	%	n	%	
IPS hostility (female)														
Intake	434	63.3	110	66.3	91	66.9	17	58.6	11	57.9	13	59.1	12	60.0
6 months	253	62.0	103	62.0	86	63.2	15	51.7	12	63.2	14	63.6	13	65.0
12 months	174	62.8	57	63.3	55	59.1	19	79.2	18	85.7	14	70.0	7	36.8
18 months	137	67.8	28	63.6	54	74.0	16	69.6	11	61.1	11	78.6	13	56.5
24 months	107	61.5	27	69.2	42	66.7	7	41.2	8	53.3	7	53.8	12	66.7
Q.-exp.	65	66.3	0	0	1	33.3	0	0	12	60.0	35	72.9	13	61.9
Sexual satisfaction (male)														
Intake	113	16.5	31	18.7	28	20.6	1	3.4	3	15.8	4	18.2	3	15.0
6 months	83	20.3	36	21.7	31	22.8	3	10.3	5	26.3	4	18.2	3	15.0
12 months	54	19.6	15	16.7	21	22.6	3	12.5	8	38.1	4	20.0	3	16.7
18 months	52	26.0	16	36.4	19	26.0	5	22.7	6	35.3	1	7.1	4	17.4
24 months	50	28.7	10	25.6	18	28.6	5	29.4	6	40.0	4	30.8	6	33.3
Q.-exp.	22	26.8	0	0	1	33.3	0	0	7	38.9	9	24.3	4	22.2
Sexual satisfaction (female)														
Intake	93	13.6	25	15.1	18	13.2	2	6.9	2	10.5	3	13.6	5	25.0
6 months	78	19.1	32	19.3	30	22.1	4	13.8	3	15.8	3	13.6	5	25.0
12 months	53	19.1	18	20.0	19	20.4	1	4.2	6	28.6	3	15.0	6	31.6
18 months	42	20.9	11	25.6	15	20.5	2	8.7	4	22.2	2	14.3	6	26.1
24 months	35	20.1	11	28.2	14	22.2	2	11.8	3	20.0	1	7.7	4	22.2
Q.-exp.	25	26.0	0	0	1	33.3	0	0	7	35.0	10	21.7	6	28.6
Marital adjustment (male)														
Intake	38	5.5	9	5.4	11	8.1	3	10.3	0	0.0	0	0.0	1	5.0
6 months	32	7.8	11	6.6	13	9.6	1	3.4	2	10.5	2	9.1	3	15.0
12 months	20	7.3	7	7.8	6	6.5	3	12.5	1	4.8	2	10.0	0	0
18 months	18	9.0	5	11.4	7	9.6	4	18.2	0	0	1	7.1	1	4.3
24 months	20	11.6	3	7.7	10	16.1	2	11.8	0	0	2	15.4	2	11.1
Q.-exp.	7	5.7	0	0	0	0	0	0	3	16.7	3	8.3	2	5.9

Table 7. Total Scores for Perceived Intrusiveness of Fertility Treatments

	Total sample			No treatment			Medication		
	Mean	SD	N	Mean	SD	N	Mean	SD	N
Intrusion (female)									
6 months	48.9	24.7	362	42.0	21.1	144	49.0	25.5	130
12 months	50.0	24.4	192	42.0	24.3	54	47.0	21.8	66
18 months	48.4	24.6	86	31.0	14.5	8	48.0	25.7	30
24 months	47.9	23.5	49	33.0	16.1	7	41.0	20.9	10
Q.-exp.	58.2	25.8	53	0.0	0.0	0	0	0.0	0
Surgery									
AID									
6 months	59.0	24.1	28	49.0	21.1	19	79.0	22.4	21
12 months	59.0	23.5	21	54.0	25.6	17	74.0	23.6	17
18 months	51.0	22.3	15	44.0	22.8	11	69.0	34.3	6
24 months	47.0	24.6	7	60.0	31.2	8	62.0	14.6	7
Q.-exp.	0	0.0	0	41.1	20.0	11	62.9	27.2	29
IVF									
AIH									
6 months	48.0	24.2	20						
12 months	48.0	16.5	17						
18 months	51.0	22.0	16						
24 months	46.0	22.7	10						
Q.-exp.	54.8	19.3	8						

Table 8. Perceived Intrusiveness of Infertility Diagnosis and Treatment into Six Life Domains for Men and Women Combined, Six Months After Intake

Group	Physical	Work	Marital	Recreation	Self	Morale
Diagnosis only (138)	2.08 _{a,1} (1.31)	2.26 _{a,1} (1.37)	2.34 _{a,1} (1.34)	2.15 _{a,1} (1.30)	2.44 _{a,1} (1.51)	3.35 _{a,2} (1.89)
Medication (123)	2.30 _{a,1} (1.59)	2.39 _{a,1} (1.49)	2.57 _{a,1} (1.53)	2.26 _{a,1} (1.53)	2.52 _{a,1} (1.67)	3.62 _{a,2} (1.99)
Surgery (25)	2.62 _{a,1} (1.44)	2.62 _{ab,1} (1.46)	2.84 _{a,1,2} (1.50)	2.66 _{a,1} (1.30)	2.51 _{a,1} (1.55)	3.38 _{a,2} (1.97)
AID (16)	2.15 _{a,1} (1.18)	2.93 _{ab,1,3} (1.52)	2.60 _{a,1} (1.44)	2.56 _{a,1} (1.35)	2.59 _{a,1} (1.44)	4.18 _{a,2,3} 2.18
AIH (19)	2.27 _{a,1,2} (1.68)	2.88 _{ab,1,2} (1.37)	2.65 _{a,1,2} (1.46)	2.25 _{a,1} (1.36)	2.42 _{a,1,2} (1.49)	3.53 _{a,3} (2.11)
IVF (16)	3.80 _{a,1} (1.54)	4.86 _{b,2,3,4} (1.51)	4.30 _{a,1,2,3} (1.46)	4.45 _{a,3} (1.48)	3.59 _{a,1} (1.88)	5.14 _{a,3,4} (2.05)

Notes: (1) Standard deviations are in parentheses. (2) Non-overlapping subscripts indicate significantly different group means (alphabetic subscripts refer to differences within columns; numeric subscripts refer to differences within rows).

Table 9A. Mean Satisfaction Rating for Women

Item	6 months			12 months			18 months			24 months		
	Total sample mean	Mean	SD	n	Mean	SD	n	Mean	SD	n	Mean	SD
Doctors' attitudes	5.08	5.15	1.63	391	5.06	1.53	216	4.85	1.47	100	5.26	1.58
Nurses' attitudes	5.82	5.84	1.24	393	5.80	1.19	217	5.61	1.25	100	6.02	1.06
Clerical personnel attitudes	5.47	5.50	1.43	394	5.59	1.36	215	5.25	1.36	100	5.52	1.36
Medical secretaries' attitudes	5.60	5.72	1.39	392	5.69	1.31	215	5.45	1.39	100	5.54	1.40
Information about diagnosis	4.50	4.68	1.64	385	4.55	1.74	216	4.26	1.62	100	4.50	1.81
Information about medical exams	4.53	4.77	1.69	391	4.65	1.68	216	4.25	1.71	100	4.44	1.74
Secondary effects of treatment	4.06	4.18	1.79	381	4.10	1.71	214	3.86	1.84	98	4.08	1.81
Information about medication	4.46	4.60	1.65	369	4.50	1.74	210	4.20	1.60	97	4.54	1.86
Information about prognosis	4.01	4.17	1.80	380	4.09	1.85	214	3.74	1.80	100	4.04	1.88
Length of diagnostic evaluation	4.57	4.72	1.72	386	4.62	1.70	216	4.21	1.69	98	4.72	1.53

Table 9A. (cont'd)

Item	Total sample mean	6 months			12 months			18 months			24 months		
		Mean	SD	n	Mean	SD	n	Mean	SD	n	Mean	SD	n
Length of treatment	4.62	4.79	1.74	367	4.63	1.68	211	4.34	1.63	99	4.73	1.59	49
Quality of medical care	5.61	5.61	1.42	378	5.48	1.33	213	5.48	1.39	99	5.86	1.21	49
Time spent discussing with doctors	4.28	4.38	1.85	390	4.20	1.82	214	3.99	1.78	99	4.56	1.93	50
Availability to answer questions	4.58	4.62	1.78	389	4.37	1.74	216	4.46	1.71	97	4.88	1.70	49
Concern of staff about health	4.42	4.60	1.78	387	4.35	1.77	217	4.07	1.76	100	4.64	1.70	50
Time to obtain an appointment	5.48	5.30	1.67	392	5.45	1.53	217	5.46	1.65	100	5.72	1.47	50
Time spent in waiting room	4.12	3.91	1.87	394	3.97	1.75	217	4.15	1.95	100	4.46	1.73	50
Availability of staff for phone contact	5.20	5.12	1.55	392	5.16	1.52	216	5.11	1.46	100	5.42	1.50	50
Speed with which test results were communicated	4.95	4.86	1.71	390	4.84	1.52	213	4.82	1.49	99	5.26	1.51	50
Emotional support from medical staff	4.31	4.31	1.68	377	4.24	1.70	214	4.15	1.68	98	4.52	1.73	50

Number of different doctors met	4.15	4.12	1.87	369	4.07	1.95	211	4.02	1.83	99	4.40	1.70	50
Information about adoption	3.18	3.20	1.81	355	3.13	1.73	197	3.00	1.64	95	3.40	1.80	47
Insistence on both partners' presence	5.04	5.12	1.67	382	5.24	1.52	211	4.77	1.93	100	5.02	1.65	49
Pressure to reach a decision	5.14	5.14	1.54	375	5.06	1.62	212	5.08	1.47	100	5.28	1.51	50
Consulted about medical decision	5.20	5.21	1.52	372	5.21	1.54	210	5.08	1.46	99	5.30	1.58	50
Movement between hospital buildings	4.46	4.34	1.63	381	4.49	1.57	212	4.37	1.71	99	4.63	1.67	49
Gentleness of physical exams	5.42	5.42	1.45	387	5.44	1.39	216	5.30	1.48	100	5.52	1.40	50
Caring of staff	5.34	5.29	1.40	388	5.30	1.35	216	5.18	1.28	100	5.60	1.26	50
Competence of nurses	5.66	5.65	1.27	386	5.56	1.22	214	5.55	1.25	100	5.86	1.13	50
Availability of specialized treatments	5.14	5.18	1.50	373	5.10	1.42	211	4.96	1.49	100	5.32	1.65	50
General satisfaction with clinic	5.35	5.37	1.43	389	5.25	1.43	217	5.17	1.36	100	5.62	1.23	50
Mean for all items	4.83	4.87			4.81			4.65			4.99		

Table 9B. Mean Satisfaction Rating for Men

Item	Total sample mean	6 months			12 months			18 months			24 months		
		Mean	SD	n	Mean	SD	n	Mean	SD	n	Mean	SD	n
Doctors' attitudes	5.07	5.25	1.54	387	5.09	1.49	215	5.01	1.63	98	4.94	1.63	51
Nurses' attitudes	5.64	5.71	1.23	386	5.58	1.24	215	5.48	1.47	98	5.78	1.08	51
Clerical personnel attitudes	5.37	5.38	1.41	385	5.32	1.34	212	5.21	1.43	98	5.56	1.11	50
Medical secretaries' attitudes	5.52	5.63	1.30	384	5.42	1.35	214	5.42	1.31	97	5.60	1.11	50
Information about diagnosis	4.53	4.74	1.69	381	4.47	1.73	215	4.34	1.66	96	4.55	1.76	49
Information about medical exams	4.56	4.69	1.70	381	4.49	1.77	214	4.34	1.63	98	4.70	1.83	50
Secondary effects of treatment	4.18	4.25	1.78	371	4.11	1.67	212	3.99	1.56	97	4.38	1.74	50
Information about medication	4.49	4.58	1.74	367	4.37	1.65	212	4.35	1.59	95	4.67	1.75	49
Information about prognosis	4.17	4.21	1.75	374	4.20	1.83	212	4.13	1.65	97	4.12	1.90	50
Length of diagnostic evaluation	4.55	4.68	1.67	372	4.49	1.62	211	4.38	1.57	95	4.64	1.56	50
Length of treatment	4.57	4.75	1.58	363	4.49	1.61	210	4.49	1.61	95	4.56	1.67	50
Quality of medical care	5.35	5.41	1.48	371	5.20	1.44	213	5.27	1.40	96	5.51	1.28	49

discussing with doctors	4.41	4.56	1.76	378	4.39	1.80	213	4.31	1.70	96	4.36	1.92	50
Availability to answer questions	4.56	4.63	1.72	381	4.45	1.77	212	4.49	1.74	97	4.65	1.75	49
Concern of staff about health	4.61	4.82	1.66	377	4.50	1.70	214	4.59	1.78	96	4.51	1.73	49
Time to obtain an appointment	4.88	4.76	1.77	381	4.82	1.78	214	4.86	1.79	96	5.06	1.77	50
Time spent in waiting room	4.21	4.14	1.77	386	4.01	1.73	214	4.07	1.58	97	4.60	1.63	50
Availability of staff for phone contact	4.94	4.94	1.52	373	4.84	1.45	206	4.68	1.41	97	5.29	1.30	48
Speed with which test results were communicated	4.77	4.80	1.64	377	4.74	1.51	211	4.67	1.30	96	4.88	1.51	50
Emotional support from medical staff	4.57	4.69	1.63	375	4.51	1.62	209	4.46	1.66	96	4.62	1.68	47
Number of different doctors met	4.31	4.44	1.74	363	4.25	1.67	208	4.16	1.77	97	4.40	1.82	48
Information about adoption	3.68	3.85	1.76	351	3.60	1.69	201	3.57	1.62	93	3.71	1.88	45
Insistence on both partners' presence	5.17	5.29	1.52	374	5.15	1.46	208	4.96	1.65	95	5.27	1.45	48
Pressure to reach a decision	5.06	5.09	1.41	369	5.04	1.40	211	5.04	1.48	96	5.08	1.44	50

Table 9B. (cont'd)

Item	Total sample mean	6 months			12 months			18 months			24 months		
		Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD	N
Consulted about medical decision	5.06	5.08	1.50	372	4.99	1.44	210	4.99	1.53	96	5.16	1.46	49
Movement between hospital buildings	4.36	4.28	1.69	372	4.44	1.52	207	4.41	1.62	97	4.29	1.71	49
Gentleness of physical exams	5.28	5.32	1.37	371	5.20	1.36	208	5.14	1.46	95	5.47	1.21	47
Caring of staff	5.29	5.27	1.41	381	5.16	1.32	211	5.21	1.35	97	5.52	1.27	50
Competence of nurses	5.53	5.48	1.29	376	5.44	1.22	209	5.44	1.41	97	5.76	1.03	49
Availability of specialized treatments	5.00	5.06	1.49	370	4.97	1.50	209	4.85	1.60	97	5.10	1.62	50
General satisfaction with clinic	5.29	5.43	1.40	384	5.15	1.44	215	5.15	1.40	97	5.42	1.18	50
Mean for all items	4.80	4.88			4.74			4.69			4.91		

Table 10. Percentage of Patients Highly Dissatisfied, by Gender

	Women (W) (average) (average) %	Men (M) (average) (average) %	6 months		12 months		18 months		24 months									
			W		M		W		M									
			n	%	n	%	n	%	n	%								
Doctors' attitudes	7	8	33	8	30	8	12	6	11	5	7	7	9	9	3	6	5	10
Nurses' attitudes	1	3	9	2	7	2	1	0	3	1	1	1	6	6	0	0	1	2
Clerical personnel attitudes	3	3	21	5	16	4	3	1	5	2	3	3	6	6	1	2	0	0
Medical secretaries' attitudes	3	2	14	4	12	3	2	1	7	3	3	3	3	3	2	4	0	0
Information about diagnosis	13	13	43	11	46	12	32	15	32	15	15	15	13	14	5	10	6	12
Information about medical exams	14	14	44	11	47	12	26	12	34	16	19	19	14	14	6	12	7	14
Secondary effects of treatment	23	18	78	20	66	18	43	20	38	18	27	28	17	18	11	22	8	16

an appointment	7	12	35	9	49	13	12	6	24	11	8	8	12	13	3	6	6	12
Time spent in the waiting room	22	17	105	27	74	19	45	21	46	21	25	25	17	18	8	16	5	10
Availability of staff for phone contact	6	6	30	8	25	7	12	6	11	5	5	5	8	8	3	6	2	4
Speed with which test results were communicated	9	8	43	11	37	10	16	8	15	7	7	7	6	6	4	8	4	8
Emotional support from medical staff	17	13	61	16	36	10	39	18	25	12	20	20	14	15	7	14	6	13
Number of different doctors met	22	16	79	21	54	15	54	26	34	16	25	25	18	19	8	16	7	15
Information about adoption	41	27	145	41	81	23	80	41	58	29	41	43	26	28	18	38	12	27
Insistence on both partners' presence	10	6	35	9	19	5	10	5	10	5	15	15	10	11	5	10	2	4
Pressure to reach a decision	6	5	22	6	17	5	19	9	9	4	6	6	6	6	2	4	2	4

Table 11A. Mean Satisfaction Rating for Women, IVF Versus Other Treatments

6 months			12 months			18 months			24 months		
Mean	SD	n	Mean	SD	n	Mean	SD	n	Mean	SD	n
Overall											
Other	151.5	34.5	362	148.8	33.8	196	143.6	33.9	147.5	36.0	65
IVF	147.7	43.2	22	162.2	29.6	18	159.4	41.2	147.3	35.8	52
Total	151.3	35.0	384	149.6	33.4	214	144.4	34.2	147.4	35.8	117
Information about possible side-effects of medical treatments											
Other	4.2	1.8	357	4.1	1.7	195	3.8	1.8	4.0	1.7	64
IVF	3.7	2.1	22	4.3	1.5	18	4.4	2.4	3.7	1.9	51
Total	4.2	1.8	379	4.1	1.7	213	3.9	1.8	3.9	1.8	115
Information about prognosis											
Other	4.1	1.8	356	4.0	1.9	195	3.7	1.8	3.7	1.8	64
IVF	4.7	1.8	22	4.8	1.7	18	4.8	1.5	4.4	1.7	52
Total	4.2	1.8	378	4.1	1.8	213	3.7	1.8	4.0	1.8	116
Time devoted by physicians for discussion											
Other	4.4	1.8	366	4.1	1.8	195	4.0	1.8	4.1	1.9	65
IVF	4.3	2.2	22	5.2	1.8	18	4.0	2.2	4.4	1.9	52
Total	4.4	1.9	388	4.2	1.8	213	4.0	1.8	4.3	1.9	117

Table 11A. (cont'd)

6 months			12 months			18 months			24 months		
Mean	SD	n	Mean	SD	n	Mean	SD	n	Mean	SD	n
Time spent in waiting room											
Other	3.9	1.9	370	3.9	1.7	198	4.1	1.9	4.1	1.8	65
IVF	4.4	1.8	22	4.8	1.7	18	4.4	2.3	3.4	1.8	51
Total	3.9	1.9	392	4.0	1.8	216	4.2	1.9	3.8	1.8	116
Emotional support received from the medical team											
Other	4.3	1.7	353	4.2	1.7	195	4.1	1.7	4.2	1.7	65
IVF	4.1	1.9	22	4.8	1.5	18	5.8	1.3	4.0	1.9	51
Total	4.3	1.7	375	4.3	1.7	213	4.2	1.7	4.1	1.8	116
Number of different doctors met											
Other	4.1	1.9	345	4.0	2.0	192	4.0	1.8	4.1	1.8	65
IVF	4.6	1.9	22	4.8	1.7	18	4.4	2.2	4.5	1.7	51
Total	4.1	1.9	367	4.1	1.9	210	4.0	1.8	4.2	1.7	116
Information received about alternative services in community (e.g., adoption)											
Other	3.3	1.8	331	3.2	1.8	180	3.0	1.6	3.0	1.9	62
IVF	2.5	1.7	22	2.6	1.4	16	3.7	3.1	2.4	1.6	44
Total	3.2	1.8	353	3.1	1.7	196	3.0	1.6	2.8	1.8	106

Table 11B. Mean Satisfaction Rating for Men, IVF Versus Other Treatments

6 months			12 months			18 months			24 months		
Mean	SD	n	Mean	SD	n	Mean	SD	n	Mean	SD	n
Overall											
Other	151.8	35.6	353	146.9	36.2	194	145.0	37.8	147.2	35.8	63
IVF	147.0	39.6	22	150.7	30.6	18	152.6	26.9	145.3	37.9	41
Total	151.5	35.8	375	147.2	35.7	212	145.4	37.2	146.5	36.5	104
Information about possible side-effects of medical treatments											
Other	4.3	1.8	347	4.1	1.7	193	4.0	1.6	4.1	1.7	63
IVF	3.7	1.8	22	4.6	1.5	18	4.2	1.1	3.9	1.8	41
Total	4.3	1.8	369	4.1	1.7	211	4.0	1.6	4.0	1.7	104
Information about prognosis											
Other	4.2	1.8	350	4.2	1.8	193	4.1	1.7	4.1	1.8	63
IVF	4.0	1.7	22	4.2	2.0	18	4.4	0.9	4.2	1.8	40
Total	4.2	1.8	372	4.2	1.8	211	4.1	1.7	4.2	1.8	103
Time devoted by physicians for discussion											
Other	4.6	1.8	354	4.4	1.8	194	4.3	1.7	4.2	1.9	63
IVF	4.4	2.0	22	4.6	1.6	18	4.2	1.5	4.5	2.0	39
Total	4.6	1.8	376	4.4	1.8	212	4.3	1.7	4.3	1.9	102

Table 11B. (cont'd)

6 months			12 months			18 months			24 months		
Mean	SD	n	Mean	SD	n	Mean	SD	n	Mean	SD	n
Time spent in waiting room											
Other	4.1	1.8	362	1.7	195	4.0	1.6	92	4.4	1.7	63
IVF	4.7	1.8	22	2.0	18	4.6	1.1	5	4.0	1.9	41
Total	4.1	1.8	384	1.7	213	4.1	1.6	97	4.2	1.8	104
Emotional support received from the medical team											
Other	4.7	1.6	351	1.6	190	4.5	1.7	91	4.3	1.7	59
IVF	4.5	2.0	22	1.6	18	4.6	1.8	5	4.5	2.0	41
Total	4.7	1.6	373	1.6	208	4.5	1.7	96	4.4	1.8	100
Number of different doctors met											
Other	4.4	1.8	339	1.7	189	4.2	1.8	92	4.1	1.9	60
IVF	4.7	1.7	22	1.4	18	4.0	1.4	5	4.1	1.9	41
Total	4.4	1.7	361	1.7	207	4.2	1.8	97	4.1	1.8	101
Information received about alternative services in community (e.g., adoption)											
Other	3.9	1.8	327	1.7	183	3.6	1.6	89	3.4	1.9	59
IVF	3.7	1.8	22	1.5	17	3.8	1.3	4	3.2	1.5	35
Total	3.9	1.8	349	1.7	200	3.6	1.6	93	3.4	1.7	94

**Table 12. Reasons for Premature Termination of Treatment
(n = 138)**

Reasons	Mean	SD	% *
1. Couple's problems	1.70	1.75	8
2. Wife's desire to have a child	2.08	1.86	7
3. Husband's desire to have a child	2.08	1.94	10
4. Wife's lack of interest	2.56	2.19	15
5. Husband's lack of interest	2.60	2.24	17
6. Risk for physical health	2.63	2.36	22
7. Too much physical suffering	2.70	2.27	18
8. Too much psychological suffering	3.62	2.49	31
9. Too expensive	2.49	2.33	19
10. Conflict in schedule	2.45	2.25	18
11. Dissatisfaction with clinic	2.52	2.13	16
12. Lack of moral support from medical team	3.13	2.42	21
13. Lack of discussion with treating physician	3.32	2.50	27
14. Lack of information about diagnosis, treatment, side-effects, and prognosis	2.97	2.39	24
15. Competence of physician	1.85	1.72	6
16. Inefficacy of treatment	3.17	2.52	29

* Percentage of respondents saying reason very important (6 or 7 on a seven-point scale).

Table 13. Summary of Significant Covariation Between Motive for Drop-Out and Satisfaction with Services and Requests for Improvements*

Reason for drop-out	Satisfaction with service **	Request for improvement in service ***
Psychological suffering (8)	Discussion time available during medical treatment (14)	Requests for more information on psychological side-effects of medical treatments (19) Be received by nurse and/or psychologist at intake (20)
Lack of moral support from medical team (12)	Time spent in medical visits (14) Moral support from team (21) Information received about other options (23) Information on side-effects of treatment (8)	
Lack of dialogue with physician (13)	Time available during medical visit (14) Support from medical team (21) Change in physician (22)	
Lack of information on diagnosis, treatment, side-effects, and prognosis (14)	Information on prognosis (10) Time available during medical visits (14)	More information on side-effects of treatment (6) More information on prognosis (7)

Table 13. (cont'd)

Reason for drop-out	Satisfaction with service **	Request for improvement in service ***
	Emotional support from medical team (21)	Be seen by nurse and/or psychologist at intake (20)
	Rotation of physicians (22)	
	Information about alternative services (23)	

- * See Appendices 4, 5, and 6.
- ** All correlations between reasons for drop-out and satisfaction are negative, $p = 0.05$.
- *** All correlations with reason for drop-out and requests for improvement are positive, $p < 0.05$.

Note: Numbers in parentheses in column 1 refer to Appendix 6, column 2 to Appendix 4, and column 3 to Appendix 5.

Table 14A. Ratings of Requests for 20 Changes in Services: Women

Item	Total sample mean	6 months		12 months		18 months		24 months	
		Mean	SD	Mean	SD	Mean	SD	Mean	SD
1. Support group	4.4	4.1	1.83	4.5	1.94	4.5	1.81	4.6	1.89
2. Psychologist	4.5	4.2	1.94	4.5	1.99	4.6	1.93	4.7	1.92
3. Documentation	5.9	5.9	1.50	6.0	1.43	5.9	1.40	5.8	1.50
4. Information sessions	5.4	5.4	1.64	5.4	1.73	5.4	1.66	5.4	1.67
5. Treatments possible *	6.0	6.0	1.31	6.1	1.34	6.0	1.37	5.9	1.52
6. Secondary effects *	6.1	6.1	1.21	6.2	1.24	6.0	1.33	6.0	1.46
7. Diagnosis *	6.1	6.2	1.19	6.3	1.16	6.1	1.16	6.0	1.41
8. Prognosis *	6.3	6.4	1.14	6.5	1.06	6.4	1.07	6.1	1.35
9. Discussion with doctor	6.0	5.9	1.41	6.1	1.22	5.9	1.28	5.8	1.40
10. Moral support from doctor	5.5	5.4	1.52	5.6	1.47	5.5	1.53	5.4	1.57
11. Physician exams *	5.8	5.8	1.41	5.9	1.32	5.8	1.39	5.7	1.44
12. Length of treatment	5.8	5.9	1.34	5.9	1.37	5.7	1.44	5.7	1.47
13. Physician contacts *	5.3	5.4	1.74	5.5	1.66	5.2	1.64	5.3	1.62
14. Decision making *	5.9	5.9	1.45	6.1	1.36	5.9	1.30	5.7	1.48
15. Waiting room	4.2	3.8	2.25	4.1	2.23	4.4	2.27	4.4	2.29
16. Time for decision	4.7	4.6	1.89	4.8	1.79	4.8	1.68	4.7	1.86
17. Other input	4.9	4.7	1.81	4.9	1.85	4.8	1.75	5.0	1.74
18. Be consulted	5.5	5.4	1.60	5.6	1.57	5.3	1.52	5.4	1.67
19. Psychological effects	5.7	5.7	1.46	5.7	1.56	5.7	1.45	5.7	1.49
20. Intake nurse/psychologist	5.1	5.0	1.94	5.3	1.88	5.1	1.73	5.1	1.79
Mean; all items	5.5	5.4		5.5		5.5		5.4	

* Exact description of each item appears in Appendix 5.

Table 14B. Ratings of Requests for 20 Changes in Services: Men

Item	Total sample mean	6 months		12 months		18 months		24 months	
		Mean	SD	Mean	SD	Mean	SD	Mean	SD
1. Support group	4.0	3.8	1.86	4.2	1.85	3.9	1.80	4.0	1.91
2. Psychologist	4.0	3.7	1.89	4.2	1.88	3.9	1.89	4.0	1.84
3. Documentation	5.4	5.4	1.75	5.5	1.62	5.3	1.64	5.3	1.74
4. Information sessions	4.8	4.8	1.82	4.9	1.83	4.9	1.73	4.8	1.84
5. Treatments possible *	5.6	5.7	1.52	5.6	1.51	5.5	1.53	5.4	1.68
6. Secondary effects *	5.7	5.9	1.45	5.8	1.46	5.6	1.58	5.6	1.63
7. Diagnosis *	5.7	5.8	1.45	5.9	1.43	5.6	1.57	5.6	1.59
8. Prognosis *	5.9	6.1	1.35	6.0	1.43	5.8	1.58	5.8	1.60
9. Discussion with doctor	5.5	5.5	1.61	5.7	1.45	5.5	1.57	5.4	1.73
10. Moral support from doctor	4.9	4.8	1.68	5.1	1.64	4.8	1.72	4.8	1.65
11. Physician exams *	5.4	5.5	1.51	5.5	1.48	5.3	1.61	5.3	1.58
12. Length of treatment	5.5	5.5	1.54	5.6	1.47	5.4	1.52	5.4	1.55
13. Physician contacts *	5.2	5.2	1.73	5.3	1.66	5.2	1.61	5.1	1.77
14. Decision making *	5.6	5.7	1.49	5.8	1.35	5.6	1.60	5.5	1.57
15. Waiting room	4.1	3.8	2.21	4.3	2.17	4.1	2.20	4.2	2.18
16. Time for decision	4.5	4.5	1.95	4.6	1.82	4.5	1.82	4.5	1.82
17. Other input	4.5	4.4	1.86	4.6	1.72	4.6	1.81	4.6	1.86
18. Be consulted	5.2	5.2	1.68	5.4	1.62	5.1	1.71	5.1	1.73
19. Psychological effects	5.3	5.4	1.63	5.5	1.62	5.1	1.76	5.3	1.72
20. Intake nurse/psychologist	4.8	4.6	1.98	5.0	1.78	4.7	1.85	4.8	1.87
Mean, all items	5.1	5.1		5.2		5.0		5.0	

* Exact description of each item appears in Appendix 5.

Table 15. Percentage of Men and Women Who Indicated Strong Request for Changes (Scored 6 or 7 on Seven-Point Scale)

Item	Overall average								6 months				12 months				18 months				24 months			
	%		women		men				%		women		%		women		%		women		%		women	
1. Support group	31	23						23.0	19.8		33.9	25.7	30.2	21.9	36.4	23.4								
2. Psychologist	35	22					29.0	18.8		36.1	25.0	35.6	23.0	39.9	22.2									
3. Documentation	70	56					68.6	55.7		69.6	59.2	68.8	54.6	71.1	56.1									
4. Information sessions	55	41					51.6	38.0		55.3	41.2	55.0	42.3	59.3	42.7									
5. Treatments possible *	71	59					68.3	62.0		74.0	60.7	72.1	60.0	70.8	55.0									
6. Secondary effects *	74	66					75.4	68.6		77.0	66.5	71.8	65.3	72.8	63.7									
7. Diagnosis *	76	65					76.4	65.5		79.0	70.6	77.2	63.1	72.8	61.8									
8. Prognosis *	82	73					82.1	76.2		86.4	73.9	83.2	72.3	76.9	69.6									
9. Discussion with doctor	69	58					67.1	55.9		76.1	61.6	69.8	59.2	63.0	55.0									
10. Moral support from doctor	53	38					53.1	36.3		56.8	43.4	52.2	37.9	49.4	35.3									
11. Physician exams *	65	54					65.3	55.5		70.3	55.1	61.2	55.4	61.8	50.0									
12. Length of treatment *	67	56					68.7	56.0		71.0	57.9	60.5	57.7	66.3	52.4									
13. Physician contacts *	53	50					56.0	48.9		57.2	52.6	46.0	51.0	51.4	49.1									
14. Decision making *	69	62					66.7	62.1		75.0	63.6	68.2	65.5	65.7	58.0									
15. Waiting room	34	32					26.9	27.4		31.6	35.2	39.7	32.5	38.4	31.2									
16. Time for decision	37	34					34.5	34.3		40.7	36.5	33.5	34.5	39.8	31.8									
17. Other input	41	34					36.7	31.0		43.0	37.0	39.3	33.3	43.0	34.1									
18. Be consulted	55	48					53.6	49.0		60.9	51.9	49.0	46.7	57.6	45.6									
19. Psychological effects *	62	54					60.9	54.2		63.6	59.2	62.7	49.2	60.5	52.4									
20. Intake nurse/psychologist	50	39					48.0	34.8		55.1	45.0	48.8	38.5	49.1	37.5									
Mean, all items	57	48					56.0	48.0		61.0	51.0	56.0	48.0	57.0	46.0									

* More information requested relating to these items.

Table 16. Percentage of Men and Women Requesting and Receiving Couple or Individual Therapy

	Intake		6 months		12 months		18 months		24 months	
	Women	Men	Women	Men	Women	Men	Women	Men	Women	Men
Desire marital therapy	15	11	12	8.0	21	11.0	18	9	17	13
Desire sex therapy	14	17	10	13.0	15	12.0	14	7	16	17
Received marital therapy	-	-	4	3.0	1	0.4	5	4	3	2
Received individual psychotherapy	-	-	3	0.5	3	0.0	2	2	3	1

Table 17A. Mean Request for Change by Treatment and Time for Women

	6 months			12 months			18 months			24 months		
	Mean	SD	n	Mean	SD	n	Mean	SD	n	Mean	SD	n
Support group												
No treatment	4.0	1.9	154	4.5	1.9	84	4.7	1.9	41	4.3	1.9	38
Medication	4.2	1.6	131	4.4	2.0	90	4.6	1.8	71	4.6	1.9	60
Surgery	3.7	1.9	26	3.8	2.1	22	3.9	1.7	21	4.2	2.2	16
AID	4.6	1.9	18	5.1	1.8	20	4.2	1.9	18	5.5	1.7	15
IVF	4.7	1.9	22	4.3	2.2	18	4.1	1.7	19	4.7	1.6	19
AIH	3.9	1.9	20	4.4	1.8	19	4.5	1.8	22	4.8	1.7	16
Sample	4.2	1.8	371	4.4	1.9	253	4.4	1.8	192	4.7	1.9	164
Psychologist												
No treatment	4.2	1.9	154	4.5	1.9	84	4.5	1.9	41	4.1	2.1	38
Medication	4.3	1.9	131	4.6	2.0	90	4.6	1.9	71	4.9	1.8	60
Surgery	3.7	2.1	26	4.0	2.1	22	4.2	2.4	21	4.2	2.0	16
AID	4.3	2.1	18	4.8	2.0	20	4.7	1.8	18	5.3	2.1	15
IVF	4.1	2.1	22	3.6	2.2	18	4.8	1.9	19	5.4	1.7	19
AIH	3.6	2.0	20	3.9	2.1	19	4.1	2.1	22	4.1	1.6	16
Sample	4.1	2.0	371	4.2	2.0	253	4.5	1.9	192	4.7	1.9	164
Documentation												
No treatment	5.9	1.5	154	5.7	1.5	84	6.0	1.3	41	5.5	1.7	38
Medication	5.9	1.4	131	6.1	1.3	90	5.8	1.4	71	6.0	1.4	60
Surgery	5.9	1.6	26	6.1	1.3	22	5.9	1.7	21	5.6	1.5	16
AID	5.1	2.3	18	6.3	1.2	20	6.1	1.2	18	6.4	0.9	15
IVF	6.0	1.6	22	5.5	2.0	18	5.8	1.7	19	6.3	1.4	19
AIH	5.6	1.7	20	5.9	1.4	19	6.1	1.4	22	5.9	1.3	16
Sample	5.7	1.5	371	5.9	1.4	253	6.0	1.4	192	6.0	1.5	164

No treatment	5.3	1.7	154	5.1	1.8	84	5.1	1.6	41	5.3	1.5	38
Medication	5.3	1.6	131	5.4	1.8	90	5.5	1.6	71	5.7	1.6	60
Surgery	4.8	1.8	26	5.8	1.4	22	5.6	2.1	21	5.1	1.7	16
AID	5.1	2.1	18	5.6	1.8	20	5.3	1.9	18	5.5	1.9	15
IVF	5.9	1.5	22	5.4	1.7	18	5.8	1.3	19	6.5	0.8	19
AIH	5.7	1.2	20	5.4	1.8	19	5.2	1.6	22	4.6	1.8	16
Sample	5.4	1.7	371	5.4	1.7	253	5.4	1.7	192	5.4	1.6	164

Treatments possible *

No treatment	6.0	1.3	154	5.8	1.6	84	6.0	1.3	41	5.5	1.7	38
Medication	6.0	1.2	131	6.2	1.2	90	5.9	1.4	71	6.2	1.3	60
Surgery	5.3	1.7	26	6.0	1.2	22	5.9	1.3	21	5.2	1.7	16
AID	5.7	1.8	18	6.4	1.2	20	6.1	1.5	18	5.5	2.0	15
IVF	6.3	0.9	22	5.9	1.7	18	5.9	1.3	19	6.5	1.0	19
AIH	6.2	1.2	20	6.4	1.0	19	6.0	1.4	22	6.1	1.5	16
Sample	5.9	1.3	371	6.1	1.4	253	6.0	1.4	192	5.8	1.5	164

Secondary effects *

No treatment	6.1	1.3	154	6.0	1.4	84	6.0	1.5	41	5.6	1.6	38
Medication	6.1	1.1	131	6.3	1.1	90	6.2	1.1	71	6.4	1.1	60
Surgery	5.7	1.5	26	6.2	1.1	22	6.2	1.3	21	5.6	1.2	16
AID	5.7	1.9	18	6.3	1.2	20	5.8	1.9	18	5.7	2.2	15
IVF	6.5	0.7	22	6.1	1.6	18	6.1	1.4	19	6.7	0.7	19
AIH	6.3	1.2	20	6.2	1.2	19	5.5	1.5	22	5.8	1.6	16
Sample	6.1	1.2	371	6.2	1.3	253	6.0	1.4	192	6.0	1.4	164

Diagnosis *

No treatment	6.2	1.2	154	6.3	1.2	84	6.3	0.9	41	5.6	1.5	38
Medication	6.2	1.1	131	6.3	1.1	90	6.1	1.1	71	6.3	1.2	60
Surgery	5.6	1.6	26	6.0	1.1	22	5.9	1.3	21	5.3	1.5	16
AID	5.8	1.7	18	6.2	1.2	20	6.1	1.6	18	5.8	2.1	15
IVF	6.4	0.9	22	6.1	1.5	18	6.0	1.6	19	6.4	1.3	19
AIH	6.5	0.9	20	6.4	1.3	19	6.2	1.2	22	6.6	0.6	16
Sample	6.1	1.2	371	6.2	1.2	253	6.1	1.2	192	6.0	1.4	164

Table 17A. (cont'd)

	6 months			12 months			18 months			24 months		
	Mean	SD	n	Mean	SD	n	Mean	SD	n	Mean	SD	n
Prognosis *												
No treatment	6.4	1.2	154	6.3	1.3	84	6.5	0.7	41	5.9	1.3	38
Medication	6.4	1.0	131	6.5	0.9	90	6.3	1.0	71	6.5	1.1	60
Surgery	5.6	1.7	26	6.4	1.0	22	6.3	1.1	21	5.5	1.5	16
AID	6.2	1.6	18	6.4	1.2	20	6.5	1.4	18	5.7	2.1	15
IVF	6.4	0.9	22	6.2	1.4	18	5.9	1.4	19	6.3	1.5	19
AIH	6.9	0.4	20	6.7	0.7	19	6.4	1.2	22	6.7	0.7	16
Sample	6.3	1.2	371	6.4	1.1	253	6.3	1.1	192	6.1	1.4	164
Discussion with doctor												
No treatment	5.9	1.3	154	5.8	1.5	84	5.9	1.2	41	5.3	1.7	38
Medication	6.0	1.3	131	6.2	1.1	90	5.9	1.3	71	6.1	1.1	60
Surgery	5.5	1.9	26	6.4	0.8	22	5.6	1.5	21	5.1	1.2	16
AID	6.1	1.8	18	6.1	1.1	20	6.1	1.2	18	5.9	1.8	15
IVF	5.9	1.6	22	6.0	1.4	18	5.5	1.5	19	6.1	1.6	19
AIH	6.0	1.5	20	6.7	0.5	19	6.4	1.3	22	5.9	1.4	16
Sample	5.9	1.4	371	6.2	1.2	253	5.9	1.3	192	5.7	1.5	164
Moral support from doctor												
No treatment	5.5	1.4	154	5.2	1.7	84	5.4	1.6	41	5.3	1.7	38
Medication	5.3	1.6	131	5.8	1.2	90	5.4	1.5	71	5.5	1.5	60
Surgery	4.7	1.8	26	5.9	1.3	22	5.4	1.7	21	5.0	1.8	16
AID	5.7	1.7	18	6.0	1.2	20	6.0	1.2	18	5.2	1.9	15
IVF	5.7	1.4	22	5.5	1.7	18	5.7	1.6	19	5.7	1.6	19
AIH	5.4	1.7	20	5.7	1.5	19	5.5	1.7	22	5.5	1.3	16
Sample	5.4	1.5	371	5.7	1.5	253	5.6	1.5	192	5.4	1.6	164

No treatment	5.8	1.4	154	5.9	1.4	84	5.8	1.3	41	5.5	1.6	38
Medication	5.7	1.4	131	5.9	1.3	90	5.8	1.3	71	5.9	1.2	60
Surgery	5.4	1.7	26	6.0	1.1	22	5.9	1.4	21	5.2	1.6	16
AID	5.4	1.7	18	6.3	1.1	20	6.3	1.2	18	5.5	1.8	15
IVF	6.0	1.2	22	5.6	1.7	18	5.4	1.6	19	6.2	1.1	19
AIH	5.9	1.7	20	5.9	1.6	19	5.5	1.6	22	5.9	1.4	16
Sample	5.7	1.4	371	5.9	1.3	253	5.8	1.4	192	5.7	1.4	164
Length of treatment *												
No treatment	5.8	1.4	154	5.9	1.4	84	5.8	1.3	41	5.5	1.6	38
Medication	5.8	1.4	131	5.9	1.3	90	5.7	1.4	71	6.0	1.2	60
Surgery	5.3	1.5	26	5.7	1.5	22	5.6	1.7	21	5.3	1.7	16
AID	5.9	1.4	18	6.4	1.0	20	6.0	1.5	18	5.3	2.2	15
IVF	6.1	1.2	22	5.5	1.7	18	5.5	1.7	19	6.2	1.2	19
AIH	5.9	1.4	20	6.2	1.2	19	5.9	1.5	22	6.1	1.2	16
Sample	5.8	1.4	371	5.9	1.4	253	5.7	1.5	192	5.7	1.5	164
Physician contacts *												
No treatment	5.4	1.7	154	5.4	1.7	84	5.1	1.6	41	5.2	1.7	38
Medication	5.2	1.8	131	5.4	1.6	90	5.2	1.6	71	5.4	1.6	60
Surgery	4.5	2.2	26	5.6	1.7	22	5.3	1.6	21	5.2	1.6	16
AID	5.8	1.2	18	6.4	1.1	20	5.7	1.7	18	5.7	1.9	15
IVF	5.9	1.6	22	4.9	1.7	18	5.4	1.4	19	5.0	1.8	19
AIH	5.5	1.6	20	5.3	1.8	19	4.5	1.9	22	4.8	1.8	16
Sample	5.4	1.8	371	5.5	1.7	253	5.2	1.6	192	5.2	1.7	164
Decision making *												
No treatment	5.9	1.4	154	5.9	1.6	84	5.8	1.4	41	5.4	1.7	38
Medication	5.7	1.5	131	6.1	1.2	90	6.1	1.2	71	5.9	1.3	60
Surgery	5.0	1.6	26	6.0	1.5	22	5.8	1.4	21	5.2	1.7	16
AID	5.6	1.5	18	6.5	0.9	20	6.1	1.6	18	5.7	2.0	15
IVF	6.2	1.3	22	5.5	1.6	18	5.9	1.3	19	6.0	1.6	19
AIH	6.1	1.4	20	6.2	1.2	19	5.8	1.4	22	6.1	1.3	16
Sample	5.8	1.5	371	6.0	1.4	253	5.9	1.3	192	5.7	1.6	164

Table 17A. (cont'd)

	6 months			12 months			18 months			24 months		
	Mean	SD	n	Mean	SD	n	Mean	SD	n	Mean	SD	n
Waiting room												
No treatment	3.7	2.2	154	3.7	2.1	84	3.7	2.2	41	3.9	2.3	38
Medication	3.8	2.2	131	4.4	2.2	90	4.7	2.2	71	4.6	2.3	60
Surgery	4.0	2.0	26	4.2	2.6	22	3.9	2.5	21	3.9	2.2	16
AID	4.1	2.6	18	4.6	1.8	20	5.3	2.1	18	4.5	2.5	15
IVF	4.4	2.8	22	4.1	2.5	18	4.6	2.1	19	5.2	2.3	19
AIH	4.1	2.7	20	4.1	2.3	19	4.1	2.4	22	3.9	2.2	16
Sample	4.0	2.3	371	4.2	2.2	253	4.4	2.3	192	4.3	2.3	164
Time for decision												
No treatment	4.7	1.8	154	4.8	1.7	84	4.9	1.7	41	5.0	1.9	38
Medication	4.6	1.8	131	5.2	1.7	90	5.1	1.5	71	5.2	1.7	60
Surgery	3.7	1.9	26	4.1	2.0	22	4.6	2.0	21	4.4	1.6	16
AID	4.3	2.2	18	5.0	1.9	20	4.8	1.8	18	3.7	2.1	15
IVF	4.4	2.0	22	4.1	1.6	18	3.9	1.6	19	4.5	2.0	19
AIH	4.2	2.0	20	4.7	2.1	19	4.2	1.8	22	3.6	1.7	16
Sample	4.3	1.9	371	4.7	1.8	253	4.6	1.8	192	4.4	1.8	164
Other input												
No treatment	4.8	1.8	154	4.8	1.8	84	4.8	1.6	41	4.8	1.7	38
Medication	4.6	1.8	131	5.1	1.7	90	5.0	1.7	71	5.2	1.5	60
Surgery	4.0	2.0	26	4.6	2.1	22	4.8	2.0	21	4.8	2.1	16
AID	4.8	2.3	18	5.0	2.1	20	4.5	1.8	18	5.0	2.3	15
IVF	5.0	1.8	22	4.4	2.1	18	4.4	1.8	19	5.3	1.8	19
AIH	4.7	1.8	20	4.8	1.9	19	4.7	2.0	22	4.1	1.5	16
Sample	4.7	1.8	371	4.8	1.8	253	4.7	1.8	192	4.9	1.7	164

No treatment	5.6	1.5	154	5.6	1.6	84	5.4	1.4	41	5.3	1.6	38
Medication	5.3	1.6	131	5.8	1.4	90	5.3	1.5	71	5.8	1.4	60
Surgery	4.6	2.0	26	4.9	2.1	22	5.3	1.8	21	5.1	1.9	16
AID	5.4	2.1	18	5.9	1.6	20	5.3	1.6	18	5.0	2.5	15
IVF	5.8	1.3	22	4.9	1.6	18	5.0	1.6	19	5.8	1.8	19
AIH	5.4	1.7	20	5.9	1.2	19	5.2	1.7	22	4.7	1.9	16
Sample	5.3	1.6	371	5.5	1.6	253	5.3	1.5	192	5.3	1.7	164

Psychological effects *

No treatment	5.7	1.5	154	5.6	1.8	84	5.7	1.3	41	5.5	1.4	38
Medication	5.7	1.5	131	6.0	1.3	90	5.8	1.5	71	6.0	1.1	60
Surgery	5.1	1.6	26	5.0	2.0	22	5.9	1.6	21	5.1	1.9	16
AID	5.7	1.7	18	6.5	1.0	20	5.6	1.6	18	5.5	2.4	15
IVF	6.4	1.0	22	5.1	1.8	18	5.5	1.5	19	5.9	1.4	19
AIH	5.3	1.7	20	5.6	1.4	19	5.5	1.6	22	5.7	1.1	16
Sample	5.6	1.5	371	5.6	1.6	253	5.7	1.5	192	5.6	1.5	164

Intake nurse/psychologist

No treatment	4.8	2.0	154	5.1	2.1	84	4.8	1.8	41	4.9	1.8	38
Medication	5.0	1.9	131	5.4	1.7	90	5.5	1.5	71	5.2	1.5	60
Surgery	5.0	1.9	26	5.1	1.8	22	4.9	2.1	21	4.6	2.2	16
AID	6.1	1.7	18	5.9	1.4	20	5.9	1.4	18	5.7	2.1	15
IVF	5.3	2.1	22	4.7	2.1	18	5.1	2.1	19	5.2	1.9	19
AIH	5.0	1.9	20	5.4	2.0	19	4.4	1.8	22	4.9	1.7	16
Sample	5.2	1.9	371	5.3	1.9	253	5.1	1.7	192	5.1	1.8	164

* More information requested relating to these items.

Table 17B. Mean Request for Change by Treatment and Time for Men

	6 months			12 months			18 months			24 months		
	Mean	SD	n	Mean	SD	n	Mean	SD	n	Mean	SD	n
Support group												
No treatment	3.6	1.9	156	4.4	1.9	85	3.9	1.8	37	3.7	1.7	36
Medication	4.0	1.8	128	3.9	1.7	89	3.6	1.8	72	4.3	1.8	59
Surgery	3.5	1.4	27	3.9	2.0	22	3.5	1.6	21	3.4	1.5	17
AID	3.8	2.3	19	5.0	1.8	20	4.5	1.8	18	4.6	2.1	15
IVF	4.8	1.7	22	4.1	1.9	18	4.9	1.8	19	5.1	1.7	15
AIH	4.0	1.5	20	3.8	1.9	17	3.9	1.6	19	2.6	1.9	18
Sample	3.9	1.9	372	4.2	1.8	251	4.1	1.8	186	4.0	1.9	160
Psychologist												
No treatment	3.6	1.9	156	4.4	1.9	85	4.1	1.9	37	3.7	1.6	36
Medication	3.8	1.9	128	3.9	1.7	89	3.9	1.8	72	4.3	1.7	59
Surgery	4.1	1.6	27	4.4	1.8	22	3.9	2.0	21	3.6	1.7	17
AID	3.5	2.2	19	5.1	1.7	20	3.9	1.9	18	5.0	1.6	15
IVF	4.0	1.7	22	3.2	2.2	18	4.2	2.1	19	5.0	1.9	15
AIH	3.5	2.0	20	3.3	2.0	17	3.1	1.8	19	2.7	1.7	18
Sample	3.8	1.9	372	4.1	1.9	251	3.9	1.9	186	4.1	1.8	160
Documentation												
No treatment	5.2	1.9	156	5.3	1.7	85	4.8	1.9	37	4.8	1.8	36
Medication	5.5	1.7	128	5.5	1.6	89	5.3	1.7	72	5.7	1.3	59
Surgery	5.0	1.4	27	5.4	1.6	22	4.4	1.9	21	4.5	2.3	17
AID	4.8	2.1	19	5.8	1.3	20	6.0	0.8	18	5.6	1.4	15
IVF	5.7	1.6	22	5.9	1.7	18	5.9	1.7	19	6.7	0.6	15
AIH	5.3	1.6	20	5.4	1.7	17	5.5	1.4	19	4.8	1.9	18
Sample	5.3	1.8	372	5.5	1.6	251	5.3	1.7	186	5.3	1.7	160

Information sessions

No treatment	4.7	1.8	156	4.8	1.9	85	4.3	1.8	37	4.7	1.7	36
Medication	4.8	1.9	128	4.6	1.8	89	5.0	1.6	72	4.7	1.7	59
Surgery	4.0	1.7	27	4.4	1.8	22	4.2	2.2	21	4.2	2.2	17
AID	4.7	2.1	19	5.4	1.6	20	5.0	1.5	18	5.3	1.3	15
IVF	5.8	1.5	22	5.4	1.7	18	5.7	1.4	19	6.3	1.0	15
AIH	4.3	1.7	20	4.5	2.1	17	5.1	1.6	19	4.3	2.2	18
Sample	4.7	1.8	372	4.9	1.8	251	4.9	1.7	186	4.9	1.8	160

Treatments possible *

No treatment	5.5	1.6	156	5.4	1.7	85	5.4	1.7	37	4.8	1.9	36
Medication	5.7	1.5	128	5.8	1.2	89	5.5	1.5	72	5.6	1.5	59
Surgery	5.5	1.5	27	5.4	1.5	22	5.0	1.9	21	4.9	1.9	17
AID	5.5	2.2	19	5.5	1.4	20	5.7	1.1	18	5.9	1.3	15
IVF	6.2	1.3	22	5.6	1.8	18	6.0	1.8	19	6.7	0.7	15
AIH	5.6	1.3	20	5.8	1.5	17	5.4	1.5	19	5.6	1.5	18
Sample	5.7	1.5	372	5.6	1.5	251	5.5	1.6	186	5.6	1.6	160

Secondary effects *

No treatment	5.7	1.5	156	5.7	1.6	85	5.2	1.9	37	4.9	1.9	36
Medication	6.0	1.4	128	6.0	1.2	89	5.7	1.6	72	5.9	1.3	59
Surgery	5.9	1.2	27	5.7	1.3	22	5.4	1.8	21	4.8	2.1	17
AID	5.3	2.1	19	5.8	1.3	20	5.8	1.1	18	6.1	1.3	15
IVF	6.2	1.3	22	5.8	1.6	18	6.1	1.4	19	6.7	0.6	15
AIH	6.1	1.2	20	5.5	1.8	17	5.6	1.6	19	5.8	1.2	18
Sample	5.9	1.5	372	5.7	1.5	251	5.6	1.6	186	5.7	1.6	160

Diagnosis *

No treatment	5.6	1.5	156	5.6	1.6	85	5.3	1.7	37	5.1	1.8	36
Medication	5.9	1.3	128	6.1	1.2	89	5.7	1.5	72	6.0	1.1	59
Surgery	5.7	1.6	27	5.5	1.3	22	5.0	2.0	21	4.8	2.1	17
AID	5.7	1.7	19	5.8	1.3	20	5.7	1.3	18	6.1	1.4	15
IVF	6.1	1.5	22	5.7	1.7	18	5.8	1.5	19	6.3	1.1	15
AIH	5.8	1.2	20	5.9	1.5	17	5.8	1.3	19	5.6	1.5	18
Sample	5.8	1.5	372	5.8	1.4	251	5.6	1.6	186	5.6	1.5	160

Table 17B. (cont'd)

	6 months			12 months			18 months			24 months		
	Mean	SD	n	Mean	SD	n	Mean	SD	n	Mean	SD	n
Prognosis *												
No treatment	5.9	1.5	156	6.0	1.6	85	5.5	1.8	37	5.1	2.1	36
Medication	6.3	1.3	128	6.1	1.3	89	5.8	1.7	72	6.2	1.0	59
Surgery	6.2	1.0	27	5.7	1.2	22	5.3	1.8	21	4.8	1.9	17
AID	6.3	1.6	19	6.2	1.3	20	6.5	0.7	18	6.4	0.9	15
IVF	6.3	1.2	22	6.1	1.4	18	5.9	1.8	19	6.5	0.9	15
AIH	6.4	0.8	20	6.1	1.5	17	6.2	1.3	19	6.1	1.4	18
Sample	6.2	1.4	372	6.0	1.4	251	5.9	1.6	186	5.8	1.5	160
Discussion with doctor												
No treatment	5.3	1.6	156	5.5	1.6	85	5.3	1.8	37	4.9	2.0	36
Medication	5.6	1.5	128	5.6	1.3	89	5.2	1.6	72	5.7	1.3	59
Surgery	5.2	1.6	27	5.8	1.3	22	5.4	1.6	21	4.7	2.3	17
AID	5.5	1.9	19	6.0	1.4	20	6.1	1.0	18	6.1	1.2	15
IVF	5.7	2.0	22	5.6	1.8	18	5.7	1.7	19	6.5	0.7	15
AIH	5.5	1.6	20	6.4	1.1	17	5.9	1.4	19	5.5	1.7	18
Sample	5.5	1.6	372	5.8	1.5	251	5.6	1.6	186	5.6	1.7	160
Moral support from doctor												
No treatment	4.7	1.7	156	4.8	1.8	85	4.4	1.7	37	4.4	1.7	36
Medication	4.7	1.6	128	5.0	1.6	89	4.8	1.7	72	5.0	1.6	59
Surgery	4.7	1.6	27	5.1	1.5	22	4.5	1.7	21	4.1	1.7	17
AID	5.3	1.7	19	5.9	1.2	20	5.7	1.2	18	5.7	1.3	15
IVF	5.4	1.8	22	5.3	1.8	18	5.2	1.8	19	5.5	1.2	15
AIH	4.5	1.9	20	4.7	1.6	17	4.2	2.1	19	4.6	1.9	18
Sample	4.9	1.7	372	5.1	1.6	251	4.8	1.8	186	4.8	1.6	160

Physician exams *

No treatment	5.3	1.6	156	5.4	1.6	85	4.7	1.8	37	4.8	1.8	36
Medication	5.6	1.4	128	5.6	1.3	89	5.3	1.7	72	5.6	1.3	59
Surgery	5.3	1.4	27	5.1	1.3	22	5.4	1.6	21	4.6	1.9	17
AID	5.4	1.7	19	5.9	1.2	20	5.5	1.5	18	5.8	1.2	15
IVF	5.5	1.8	22	5.5	1.9	18	5.7	1.7	19	6.1	1.3	15
AIH	5.7	1.0	20	5.2	1.4	17	5.4	1.4	19	5.2	1.5	18
Sample	5.5	1.5	372	5.5	1.5	251	5.4	1.7	186	5.3	1.6	160

Length of treatment *

No treatment	5.3	1.6	156	5.5	1.6	85	4.9	1.7	37	5.0	1.9	36
Medication	5.7	1.4	128	5.6	1.3	89	5.4	1.5	72	5.7	1.2	59
Surgery	5.4	1.5	27	5.6	1.3	22	5.2	1.6	21	4.5	1.9	17
AID	5.7	1.5	19	5.7	1.3	20	5.8	1.3	18	5.7	1.4	15
IVF	5.5	1.9	22	5.6	1.8	18	5.7	1.8	19	6.4	1.0	15
AIH	5.8	1.3	20	5.6	1.5	17	5.7	1.3	19	5.4	1.5	18
Sample	5.6	1.5	372	5.6	1.4	251	5.5	1.6	186	5.5	1.5	160

Physician contacts *

No treatment	5.0	1.8	156	5.4	1.6	85	5.2	1.5	37	4.7	1.9	36
Medication	5.3	1.7	128	5.2	1.6	89	5.2	1.7	72	5.3	1.7	59
Surgery	4.5	1.7	27	4.9	1.7	22	5.0	1.6	21	4.3	2.0	17
AID	5.8	1.5	19	5.7	1.3	20	5.6	1.6	18	6.1	1.2	15
IVF	5.5	1.9	22	5.2	2.0	18	5.5	1.6	19	5.6	1.5	15
AIH	4.7	1.8	20	5.0	2.0	17	5.2	1.8	19	4.9	2.0	18
Sample	5.1	1.8	372	5.2	1.7	251	5.3	1.6	186	5.1	1.8	160

Decision making *

No treatment	5.6	1.6	156	5.7	1.4	85	5.3	1.8	37	5.3	1.8	36
Medication	5.7	1.5	128	5.8	1.4	89	5.6	1.6	72	5.7	1.3	59
Surgery	5.4	1.3	27	5.7	1.3	22	5.1	2.1	21	4.7	1.8	17
AID	5.7	1.3	19	6.3	1.1	20	5.9	1.1	18	5.5	1.9	15
IVF	6.1	1.4	22	5.8	1.6	18	5.6	1.9	19	6.3	1.0	15
AIH	5.7	1.4	20	5.8	1.2	17	5.8	1.4	19	5.9	1.4	18
Sample	5.7	1.5	372	5.8	1.3	251	5.6	1.7	186	5.6	1.6	160

Table 17B. (cont'd)

	6 months			12 months			18 months			24 months		
	Mean	SD	n	Mean	SD	n	Mean	SD	n	Mean	SD	n
Waiting room												
No treatment	3.7	2.3	156	4.1	2.2	85	4.0	2.3	37	4.2	2.1	36
Medication	3.7	2.1	128	4.1	2.3	89	3.9	2.1	72	4.0	2.1	59
Surgery	3.3	1.8	27	4.4	1.9	22	4.1	2.1	21	3.2	1.9	17
AID	4.7	2.3	19	5.6	1.6	20	5.3	2.2	18	4.9	2.3	15
IVF	4.0	2.3	22	4.2	2.2	18	4.5	2.4	19	5.5	1.7	15
AIH	3.9	2.3	20	4.5	2.3	17	3.9	2.3	19	4.3	2.4	18
Sample	3.9	2.2	372	4.5	2.2	251	4.3	2.2	186	4.3	2.2	160
Time for decision												
No treatment	4.6	2.0	156	4.5	1.8	85	4.2	1.8	37	4.6	2.0	36
Medication	4.5	1.9	128	4.7	1.8	89	4.6	1.8	72	4.8	1.8	59
Surgery	4.1	2.1	27	4.7	1.8	22	4.2	2.0	21	3.6	1.4	17
AID	4.9	1.7	19	5.4	1.5	20	4.8	1.8	18	4.9	2.2	15
IVF	4.0	1.8	22	4.5	1.7	18	4.8	1.8	19	5.3	1.2	15
AIH	3.6	1.8	20	4.5	1.9	17	3.9	2.0	19	3.6	1.8	18
Sample	4.3	1.9	372	4.7	1.8	251	4.4	1.8	186	4.5	1.8	160
Other input												
No treatment	4.5	1.9	156	4.5	1.7	85	4.1	1.6	37	4.7	2.0	36
Medication	4.6	1.8	128	4.5	1.8	89	4.5	1.8	72	4.9	1.6	59
Surgery	3.9	1.7	27	4.7	1.5	22	4.4	1.9	21	3.6	1.5	17
AID	4.8	1.9	19	5.7	1.5	20	4.9	2.0	18	5.1	2.0	15
IVF	4.5	2.1	22	4.9	1.6	18	4.5	2.0	19	5.2	1.5	15
AIH	3.3	2.0	20	4.0	1.9	17	4.3	2.1	19	2.9	1.9	18
Sample	4.3	1.9	372	4.7	1.7	251	4.5	1.9	186	4.4	1.9	160

Be consulted

No treatment	5.1	1.8	156	5.2	1.7	85	5.1	1.6	37	4.9	1.7	36
Medication	5.4	1.6	128	5.4	1.6	89	5.2	1.7	72	5.5	1.5	59
Surgery	4.7	1.6	27	5.3	1.2	22	4.8	1.6	21	3.9	1.8	17
AID	5.5	1.5	19	6.2	1.2	20	5.4	1.8	18	5.6	1.8	15
IVF	5.5	1.6	22	5.4	1.5	18	4.9	2.0	19	6.1	1.1	15
AIH	4.8	1.7	20	4.7	2.0	17	4.4	2.0	19	3.9	1.8	18
Sample	5.1	1.7	372	5.4	1.6	251	5.0	1.8	186	5.0	1.7	160

Psychological effects *

No treatment	5.4	1.7	156	5.4	1.7	85	5.1	1.6	37	5.0	1.8	36
Medication	5.5	1.6	128	5.5	1.6	89	5.1	1.8	72	5.3	1.6	59
Surgery	4.6	1.6	27	5.5	1.4	22	4.9	2.0	21	4.2	1.9	17
AID	5.7	1.5	19	6.4	0.9	20	5.3	1.8	18	6.3	1.0	15
IVF	5.6	1.6	22	5.4	1.7	18	5.7	1.8	19	6.1	1.1	15
AIH	5.0	1.7	20	4.8	2.0	17	4.7	2.1	19	4.8	2.0	18
Sample	5.3	1.7	372	5.5	1.6	251	5.1	1.8	186	5.3	1.7	160

Intake nurse/
psychologist

No treatment	4.5	1.9	156	4.9	2.1	85	4.6	1.9	37	4.6	1.9	36
Medication	4.8	2.0	128	5.0	1.7	89	4.7	1.7	72	4.7	1.7	59
Surgery	3.8	2.1	27	5.3	1.4	22	4.3	2.1	21	4.2	1.9	17
AID	5.5	1.8	19	5.9	1.4	20	5.3	1.7	18	6.3	0.9	15
IVF	4.4	2.2	22	4.8	1.8	18	4.6	1.9	19	5.4	1.2	15
AIH	4.2	1.8	20	4.6	1.7	17	3.7	2.4	19	4.1	2.4	18
Sample	4.5	2.0	372	5.1	1.8	251	4.5	1.9	186	4.9	1.8	160

* More information requested relating to these items.

Appendix 1: Couples Consent Form

We view fertility and pregnancies as a joint undertaking by both partners in a relationship. In order to provide a high-level service, we request that all patients and their partners be present from the very first day at the clinic. We anticipate a three-hour meeting, which will include an interview with a doctor and a completion of a series of questionnaires concerning your psychosocial functioning — presently the object of research study by the group. This first meeting is necessary. The goal of the research project is to study the evolution of psychosocial functioning in clients who consult the fertility clinic. Every six months, for the next two years, we request that you and your partner once again complete the psychosocial tests, which will take between 60 and 80 minutes of your time. The results of the questionnaires will be strictly confidential and will be used only to improve the care you receive from our team.

Your partner will not have access to the information that you provide in the questionnaires; only your doctor and members of the research team will be allowed to receive this information. The information will by no means be used to limit your access to necessary medical treatment and will serve only to improve its quality.

In acknowledgment of the expenses occasioned by the appointments to complete the psychosocial tests (parking, transport costs, babysitting fees, meals), the research team will reimburse you with a sum of as much as \$30 per visit.

It is understood that at any time during the next two years you will have the option to withdraw from the present study.

I read and understood the information above and agree to participate in the study according to the conditions mentioned above.

WOMEN:

Name and first name:

Address:

Date:
Signature

MEN:

Name and first name:

Address:

Date:
Signature

Signature of project manager:

Appendix 2: Questionnaire Related to the History of the Patient's Infertility Problem*

File no.: _____

The couple was met by:

Date:

Cultural background:

Man:

Woman:

Religion:

Man:

Woman:

To what extent do you practise your religion:

- 1) not at all
- 2) a little
- 3) moderately
- 4) very much

Years of schooling:

Net annual income:

Do you already have any children (if yes, how many?)

Conceived:

	Naturally	Adopted	With the help of treatment
a) by the couple	a) medication	b) surgery	c) AI partner/spouse
b) by the man	a) medication	b) surgery	c) AI partner/spouse

* Chatel et al. (1987), reproduced here by permission.

Conceived:

- c) by the woman a) medication b) surgery c) AI partner/spouse
- a) by the couple d) AI unknown e) IVF
- b) by the man d) AI unknown e) IVF
- c) by the couple d) AI unknown e) IVF

How long:

- a) Have you known each other? Have you been _____ or been _____
(dating, cohabitation, marriage) married living together?

File no.: _____

Date: _____

Sex: F ____ M ____

Questionnaire related to the history of the
patient's infertility problem
(to be answered separately)

Conjugal relationship

1. At the present time, how many children do you wish to have?

0 ____ 1 ____ 2 ____ 3 ____ 4+ ____
number undetermined ____
I never gave it any thought ____

2. Presently, your desire to have a child is: (circle the corresponding number)

1 = weak 2 = fairly weak 3 = fairly strong

4 = very strong 5 = extremely strong

3. Your partner's present desire to have a child seems to you: (circle the corresponding number)

1 = weak 2 = fairly weak 3 = fairly strong

4 = very strong 5 = extremely strong

4. Has the problem of infertility changed anything in your conjugal relationship? (circle the corresponding number)

1 = great deterioration 2 = slight deterioration 3 = no change
4 = slight improvement 5 = great improvement

Has the problem of infertility changed anything in your sexual relations? (circle the corresponding number)

5. With regard to satisfaction

1 = great improvement 2 = slight improvement 3 = no change
4 = slight deterioration 5 = great deterioration

6. With regard to frequency

1 = much less often 2 = less often 3 = no change
4 = more often 5 = much more often

7. With regard to desire

1 = much greater 2 = slightly greater 3 = no change
4 = slightly less 5 = much less

8. What is the frequency of your sexual relations at this time? (circle the corresponding number)

1) once a day	2) 3-4 times per week
3) twice a week	4) once a week
5) once every 2 weeks	6) once a month
7) less than once a month	8) no sexual relations

9. When you think about your sexual relationship, how do you feel?

1) not at all anxious/stressed	2) a bit anxious/stressed
3) fairly anxious/stressed	4) very anxious/stressed

Sometimes during a couple's life together, it is possible that sexual difficulties may arise. We would like to know if this is your present situation.

Female partner: Are you presently experiencing one or many of the following sexual problems?

10. Diminishment of sexual desire: a permanent or general lack of sexual desire.

Yes _____

No _____

11. Lack of sexual excitement: partial or complete inability to reach or maintain sexual excitement up to the end of intercourse.

Yes _____

No _____

12. Difficulty or inability to achieve orgasm.

Yes _____

No _____

13. Vaginism: painful contraction of a vaginal muscle which renders penetration impossible.

Yes _____

No _____

14. Dyspareunia: sexual relations are accompanied by repeated and persistent pain in the genital area.

Male partner: Are you presently experiencing one or many of the following sexual problems?

10. Diminishment of sexual desire: a permanent or general lack of sexual desire.

Yes _____

No _____

11. Lack of sexual excitement: partial or complete inability to reach or maintain an erection during sexual relations.

Yes _____

No _____

12. Premature ejaculation: involuntary ejaculation (absence of voluntary control over ejaculation).

Yes _____

No _____

13. Sexual inhibition: repeated and persistent inability to achieve orgasm as demonstrated by a delay in, or absence of, ejaculation after a period of sexual excitement.

Yes _____

No _____

14. Dyspareunia: sexual relations are accompanied by repeated and persistent pain in the genital area.

Yes _____

No _____

Concerning your infertility problem:

15. Do you ever blame yourself?

- 1) not at all 2) a bit 3) somewhat 4) very much

16. Do you ever blame your partner?

- 1) not at all 2) a bit 3) somewhat 4) very much

17. Do you presently feel the need to attend marital counselling because of your infertility problem?

- 1) not at all 2) a bit 3) somewhat 4) very much

18. Do you presently feel the need to consult a health professional in order to discuss matters concerning sexual relations with your partner?

- 1) not at all 2) a bit 3) somewhat 4) very much

19. Within the last 6 months, have you attended marital therapy for a problem related to infertility? (in other words, have you consulted with a psychologist, sexologist, social worker... with your partner?)

Yes _____ if yes, how many sessions _____ No _____

20. Within the last 6 months, have you attended individual therapy for a problem related to infertility? (in other words, have you consulted with a psychologist, sexologist, social worker... with your partner?)

Yes _____ if yes, how many sessions _____ No _____

Medical procedures:

21. Are you presently taking drugs or medication possibly affecting your mood?

Yes _____ No _____

If yes, which ones _____

What solution(s) have been foreseen by the medical team with respect to your infertility? (circle one or many items)

22. Artificial insemination with donor

23. Artificial insemination (partner as donor)

24. IVF

25. Source (artificial insemination with stimulation of the ovaries by medication)
26. Medication (excluding medication taken as part of the IVF and "source" programs)
27. Surgery (tuboplasty)
28. Endometriosis surgery
29. Laparoscopy
30. I don't know

What solution(s) do you presently foresee for your infertility? (circle one or several answers)

31. Artificial insemination (donor-unknown)
32. Artificial insemination (donor-partner)
33. IVF (test-tube baby)
34. Source (artificial insemination with stimulation of the ovaries by medication)
35. Medication (excluding medication taken as part of the IVF and "source" programs)
36. Surgery (tuboplasty)
37. Endometriosis surgery
38. Laparoscopy
39. Adoption
40. Surrogate motherhood
41. Separation
42. Extramarital relations
43. I don't know

44. What, in your opinion, are your chances of conceiving a child and having a pregnancy successfully carried to term? (circle the appropriate category)

- | | | | |
|-------------|-------------|-------------|--------------------|
| 1) 0 - 15% | 3) 31 - 45% | 5) 61 - 75% | 7) 91% and greater |
| 2) 16 - 30% | 4) 46 - 60% | 6) 76 - 90% | 8) I don't know |

45. According to your doctor, what are your chances of conceiving a child? (circle the appropriate category)

- | | | | |
|-------------|-------------|-------------|--------------------|
| 1) 0 - 15% | 3) 31 - 45% | 5) 61 - 75% | 7) 91% and greater |
| 2) 16 - 30% | 4) 46 - 60% | 6) 76 - 90% | 8) I don't know |

Reactions of your immediate family and friends

46. Have you discussed with people close to you your difficulty in conceiving a child?

Yes _____ No _____

(If no, proceed to question 61.)

If yes, with whom and to what extent?

	not at all	a bit	somewhat	very much
47. parents	1	2	3	4
48. parents-in-law	1	2	3	4
49. brothers, sisters	1	2	3	4
50. brothers-in-law, sisters-in-law	1	2	3	4
51. friends	1	2	3	4

52. If yes, how do your friends and family respond to your difficulty in conceiving a child? (circle the corresponding number)

- 1) in an especially positive manner 2) without reaction
3) in an especially negative manner

Specify:

	not at all	a bit	somewhat	very much
53. pressure	1	2	3	4
54. tasteless humour, disagreeable remarks	1	2	3	4
55. encouragement, reassurance	1	2	3	4
56. empathy, closeness	1	2	3	4
57. withdrawal, distance, coldness	1	2	3	4
58. anxiously	1	2	3	4
59. guilt	1	2	3	4
60. other	1	2	3	4

61. Have you spoken to members of your entourage about solutions you foresee concerning your infertility problem?

Yes _____ No _____

(If no, proceed to question 75.)

	not at all	a bit	somewhat	very much
62. parents	1	2	3	4
63. parents-in-law	1	2	3	4
64. brothers, sisters	1	2	3	4
65. brothers-in-law, sisters-in-law	1	2	3	4
66. friends	1	2	3	4

67. If yes, do your friends and family respond to the solutions you foresee (circle the corresponding number)

- 1) in an especially positive manner 2) without reaction
3) in an especially negative manner

Specify:

	not at all	a bit	somewhat	very much
68. favourable pressure or advice	1	2	3	4
69. unfavourable pressure or advice	1	2	3	4
70. empathy, closeness	1	2	3	4
71. lack of understanding	1	2	3	4
72. distance, coldness	1	2	3	4
73. anxiously, worriedly	1	2	3	4
74. other	1	2	3	4

Means to have a child

75. Generally speaking, are you in favour of the new ways of having children, such as artificial insemination, IVF (test-tube babies), and surrogate motherhood? (circle the corresponding number)

completely in favour	somewhat in favour	somewhat in disfavour	completely in disfavour
1	2	3	4

More specifically, are you in favour of the procedures mentioned above? (circle the corresponding number)

	very much in favour	moderately in favour	moderately in disfavour	very much in disfavour
76. artificial insemination	1	2	3	4
77. IVF (test-tube baby)	1	2	3	4
78. surrogate motherhood	1	2	3	4

Do you feel well informed about the following procedures? (circle the corresponding number)

	very informed	moderately informed	poorly informed	not at all informed
79. artificial insemination	1	2	3	4
80. IVF (test-tube baby)	1	2	3	4
81. surrogate motherhood	1	2	3	4

Personally, do you feel ready as a couple to undertake the following means to have a child? (circle the corresponding number)

	not at all ready	not quite ready	somewhat ready	completely ready
82. medication	1	2	3	4
83. surgery	1	2	3	4
84. artificial insemination donor-partner	1	2	3	4
85. artificial insemination donor-unknown	1	2	3	4
86. IVF (test-tube baby)	1	2	3	4
87. surrogate motherhood	1	2	3	4
88. adoption	1	2	3	4
89. separation	1	2	3	4
90. extramarital relations	1	2	3	4

Future prospects

If your current pregnancy plan is not successful, how do you foresee your future?

	completely disagree	somewhat disagree	somewhat agree	completely agree
91. My life would be empty	1	2	3	4
92. Life would not be worth living	1	2	3	4
93. I can't even imagine such a thing	1	2	3	4

	completely disagree	somewhat disagree	somewhat agree	completely agree
94. I will find other means to fulfil myself	1	2	3	4
95. I believe that my partner would do better to find someone else. I don't want to deprive him/her of that.	1	2	3	4
96. I will try all possible means whatever the cost. I don't believe that I will never be able to have a child.	1	2	3	4

Appendix 3: Perceived Intrusiveness of Fertility Treatment Scale*

First Recall

File no.: _____

Date: _____

Sex: F ____ M ____

Medical examinations and treatment require a considerable amount of time and effort. It may be that the medical procedures you have undertaken to deal with your infertility have been an intrusion in your daily life. Using the scale below, please indicate by circling the appropriate number the extent to which the medical treatments undergone over the last six months with respect to your infertility (or the treatments undergone by your partner) have interfered with, hindered, or imposed upon the different aspects of your life listed below:

* Wright and Sabourin (1988), reproduced here by permission.

	1	2	3	4	5	6	7
	not at all			moderately			very much
1. professional activities (relations with colleagues, efficiency at work)						1 2 3 4 5 6 7	
2. social relationships						1 2 3 4 5 6 7	
3. family relations						1 2 3 4 5 6 7	
4. leisure (active and passive)						1 2 3 4 5 6 7	
5. physical health						1 2 3 4 5 6 7	
6. morale						1 2 3 4 5 6 7	
7. financial situation						1 2 3 4 5 6 7	
8. marital relationship						1 2 3 4 5 6 7	
9. sexual relations						1 2 3 4 5 6 7	
10. social support (support offered by your entourage)						1 2 3 4 5 6 7	
11. duties at home (domestic upkeep)						1 2 3 4 5 6 7	
12. the sharing of responsibilities						1 2 3 4 5 6 7	
13. self-esteem (e.g., the opinion you have of yourself)						1 2 3 4 5 6 7	
14. social acceptance (e.g., being accepted by the people in your entourage)						1 2 3 4 5 6 7	
15. sleep						1 2 3 4 5 6 7	
16. moments of relaxation						1 2 3 4 5 6 7	
17. diet						1 2 3 4 5 6 7	

**If you have not undergone any of the following treatments, write
'does not apply':**

	1	2	3	4	5	6	7
	not at all			moderately			very much
1. Artificial insemination with donor						1 2 3 4 5 6 7	
2. Artificial insemination (partner as donor)						1 2 3 4 5 6 7	
3. IVF						1 2 3 4 5 6 7	

	1	2	3	4	5	6	7
	not at all			moderately			very much
4. Source (artificial insemination involving medical stimulation of the ovaries)						1 2 3 4 5 6 7	
5. Medication (this excludes medication taken as part of the <i>in vitro</i> fertilization and 'source' treatment programmes)						1 2 3 4 5 6 7	
6. Surgery (tuboplasty)						1 2 3 4 5 6 7	
7. Surgical endometriosis						1 2 3 4 5 6 7	
8. Laparoscopy						1 2 3 4 5 6 7	

Appendix 4: Patient Satisfaction Form*

First Recall
Satisfaction with services

File no.: _____

Date: _____

Sex: F ____ M ____

The staff at the fertility clinic wishes to know your degree of satisfaction with regard to the services you have received. The information gathered will be analyzed collectively and not individually so that you need to have no qualms in completing the questionnaire.

Using the scale below, as well as the services listed, please indicate, by circling the appropriate number, the extent to which you feel satisfied with the services you have received at Hôpital St-Luc's fertility clinic.

* Based on Sabourin et al. (1991), reproduced here by permission.

	1	2	3	4	5	6	7
	not at all satisfied			fairly satisfied			very satisfied
1. Attitude of physicians						1 2 3 4 5 6 7	
2. Attitude of the nursing staff						1 2 3 4 5 6 7	
3. Attitude of the registration personnel						1 2 3 4 5 6 7	
4. Attitude of the personnel during initial registration						1 2 3 4 5 6 7	
5. Information received with regard to the diagnosis made						1 2 3 4 5 6 7	
6. Information received with regard to the type of treatment and medical examinations						1 2 3 4 5 6 7	
7. Information received concerning secondary effects which may result from the diverse medical procedures						1 2 3 4 5 6 7	
8. Information received concerning medication treatment to be followed at home						1 2 3 4 5 6 7	
9. Information received concerning the prognosis, i.e., your chances of conceiving and carrying a pregnancy to term						1 2 3 4 5 6 7	
10. Duration of investigation (medical examinations)						1 2 3 4 5 6 7	
11. Length of treatment						1 2 3 4 5 6 7	
12. Quality of medical care received						1 2 3 4 5 6 7	
13. Time allotted to you during the medical appointments (discussion time)						1 2 3 4 5 6 7	
14. Readiness of physicians and nurses to answer your questions						1 2 3 4 5 6 7	
15. Concern on the part of physicians and nurses for your physical health (or that of your partner)						1 2 3 4 5 6 7	
16. Waiting time in order to obtain an appointment						1 2 3 4 5 6 7	
17. Length of time spent in the waiting room						1 2 3 4 5 6 7	

	1	2	3	4	5	6	7
	not at all satisfied			fairly satisfied			very satisfied
18. Readiness of personnel to answer questions on the telephone						1 2 3 4 5 6 7	
19. Speed with which you obtained results of diverse examinations and treatments you underwent						1 2 3 4 5 6 7	
20. Emotional support received from the medical team						1 2 3 4 5 6 7	
21. Rotation of physicians						1 2 3 4 5 6 7	
22. Information received as to the various services offered by the community (adoption)						1 2 3 4 5 6 7	
23. Recommendations that your partner be present during medical visits						1 2 3 4 5 6 7	
24. Time allotted to reflect before making a decision						1 2 3 4 5 6 7	
25. The degree to which you were consulted before a decision was reached						1 2 3 4 5 6 7	
26. Moving from one building to another (for various examinations)						1 2 3 4 5 6 7	
27. Sensitivity displayed during physical examinations						1 2 3 4 5 6 7	
28. Individual attention given by the personnel						1 2 3 4 5 6 7	
29. Satisfaction with the care you received from the nursing staff						1 2 3 4 5 6 7	
30. Accessibility of treatments						1 2 3 4 5 6 7	
31. General satisfaction with the clinic						1 2 3 4 5 6 7	

Appendix 5: Patient's Suggestions for Improvements in Services*

First Recall

File no.: _____

Date: _____

Sex: F ____ M ____

We wish to have your comments concerning the changes we propose to make at the fertility clinic. The budget and time of the medical staff are limited. We would like, despite this constraint, to know the activities that you think could be improved. It may be that the improvements mentioned below will appear more or less desirable. We are, therefore, interested in knowing what appears most important to you. The information gathered will be analyzed collectively, and not individually, so that you may feel comfortable in completing the questionnaire.

It is:

	1	2	3	4	5	6	7
	not at all			fairly			very
	important			important			important
1. to have access to a support group (discussions with others who have experienced similar problems)						1 2 3 4 5 6 7	
2. to have access to psychological help from a resource person						1 2 3 4 5 6 7	
3. to have greater access to documentation on the subject of infertility, its treatment, and available resources (books, films, pamphlets, videocassettes)						1 2 3 4 5 6 7	
4. to attend individual or group briefings regarding diagnosis, treatments, and secondary effects resulting from the various methods of treatment						1 2 3 4 5 6 7	
5. to obtain additional information from the medical staff (doctors and nurses) regarding the different treatments possible						1 2 3 4 5 6 7	

* Sabourin and Wright (1988), reproduced here by permission.

	1	2	3	4	5	6	7
	not at all important			fairly important			very important
6. to obtain additional information from the medical staff (doctors and nurses) regarding physical secondary effects which may result from medical intervention						1 2 3 4 5 6 7	
7. to obtain additional information from the medical staff (doctors and nurses) concerning the diagnosis made						1 2 3 4 5 6 7	
8. to obtain additional information from the medical staff (doctors and nurses) regarding the prognosis, as well as the chances of conceiving and carrying a pregnancy to term						1 2 3 4 5 6 7	
9. to increase the time allotted for discussion with the medical staff (doctors and nurses)						1 2 3 4 5 6 7	
10. to obtain additional moral support from the medical staff (doctors and nurses) throughout the process of waiting for the results, obtaining them, and making a decision						1 2 3 4 5 6 7	
11. to obtain additional information from the medical staff (doctors and nurses) concerning the various physical examinations						1 2 3 4 5 6 7	
12. to obtain additional information from the medical staff (doctors and nurses) regarding the duration of examinations and treatment						1 2 3 4 5 6 7	
13. to show greater sensitivity and respect, particularly during physical examinations						1 2 3 4 5 6 7	
14. to obtain sufficient information, in a detailed and personal manner, in order to facilitate the process of making decisions						1 2 3 4 5 6 7	
15. to provide a waiting room which is arranged in such a way as to avoid contact with women who are pregnant, or who are undergoing procedures for abortion						1 2 3 4 5 6 7	

1	2	3	4	5	6	7
not at all			fairly			very
important			important			important
16. to have more time to consider the various treatments proposed before reaching any decisions					1 2 3 4 5 6 7	
17. to consider materials or techniques dealing with infertility, other than from medical sources					1 2 3 4 5 6 7	
18. to be properly consulted at the moment when medical procedures begin or are about to be undertaken					1 2 3 4 5 6 7	
19. to obtain further information from the medical staff (doctors and nurses) regarding the psychological consequences which may result from the various stages of the medical process					1 2 3 4 5 6 7	
20. to meet a member of the nursing staff, as well as a psychologist, on the first visit to the fertility clinic					1 2 3 4 5 6 7	

Appendix 6: Questionnaire Concerning the Cessation of Fertility Treatment*

Date of telephone call:

1. _____ 2. _____ 3. _____

File no.: _____

Name of patient: _____

Telephone no.: Home _____
Work _____

* Sabourin and Wright (1990), reproduced here by permission.

Past history of fertility consultations

1. Have you previously consulted another fertility clinic?

Yes_____ No_____

2. If yes, for how many months?

number of months: _____

Cessation of medical procedures

3. For how long did you consult the fertility clinic? (from the first to the last consultation)

a) number of months: _____

b) number of visits: _____

4. When did you cease medical procedures?

1) Before a diagnosis was attempted _____

2) During diagnosis testing _____

3) After a diagnosis was reached _____

4) During treatment _____

If programme was abandoned during treatment

5. What treatment(s) did you receive? _____

1) Artificial insemination (unknown donor) _____

2) Artificial insemination (husband) _____

3) IVF _____

4) SOURCE (AID or AI and ovarian stimulation) _____

5) Medication (this excludes medication taken within the SOURCE or *in vitro* fertilization treatment programmes) _____

6) Surgery (tuboplasty) _____

7) Surgery (endometriosis) _____

6. Following which treatment(s) did you abandon the programme?

1) AID _____

2) AI _____

3) IVF _____

4) SOURCE (AI or AID and ovarian stimulation) _____

5) Medication (this excludes medication taken within the SOURCE or *in vitro* fertilization treatment programmes) _____

6) Surgery (tuboplasty) _____

7) Surgery (endometriosis) _____

8) Laparoscopy _____

7. Was there another treatment recommended by the medical team?

Yes _____ No _____

8. If yes, before which type of medical procedure did you abandon the programme?

1) AID _____

2) AI _____

3) IVF _____

4) SOURCE (AI, AID and ovarian stimulation) _____

5) Medication (this excludes medication taken within the SOURCE or *in vitro* fertilization treatment programmes) _____

6) Surgery (tuboplasty) _____

7) Surgery (endometriosis) _____

8) Laparoscopy _____

9. For what reasons(s) did you abandon the medical procedures?

- | | |
|---|------------------|
| 1) No treatment is available | Yes ____ No ____ |
| 2) Necessary information was received | Yes ____ No ____ |
| 3) Received treatment elsewhere — changed hospital | Yes ____ No ____ |
| 4) Decided to adopt | Yes ____ No ____ |
| 5) Decided to seek the services of a surrogate mother | Yes ____ No ____ |
| 6) Decided to engage in extramarital relations | Yes ____ No ____ |

10. To what extent did the following reasons play a role in your decision to abandon medical procedures?

	very little/very much						
1) Marital problems	1	2	3	4	5	6	7
2) Woman re-evaluated her decision to bear children	1	2	3	4	5	6	7
3) Man re-evaluated his decision to father a child	1	2	3	4	5	6	7
4) Loss of interest or motivation on the woman's part	1	2	3	4	5	6	7
5) Loss of interest or motivation on the man's part	1	2	3	4	5	6	7
6) The treatment entailed too many health risks	1	2	3	4	5	6	7
7) The treatment entailed excessive physical discomfort	1	2	3	4	5	6	7
8) The treatment entailed excessive psychological discomfort	1	2	3	4	5	6	7
9) Lack of money, treatment was too costly	1	2	3	4	5	6	7
10) Lack of time on the patient's part	1	2	3	4	5	6	7

very little/very much

- | | | | | | | | |
|--|---|---|---|---|---|---|---|
| 11) Dissatisfaction with the service offered by the clinic (reception, waiting time, etc.) | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 12) Lack of moral and emotional support from the medical staff | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 13) The doctor was not sufficiently available for discussion | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 14) Lack of information concerning treatment, side-effects, or prognosis | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 15) Competency of the medical staff | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 16) The treatment was not effective | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 17) Other reason(s). Specify: | | | | | | | |

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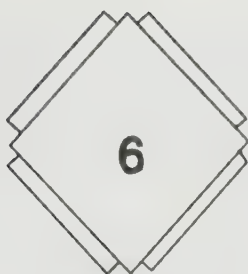
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Life Quality, Psychosocial Factors, and Infertility: Selected Results from a Five-Year Study of 275 Couples

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Executive Summary

This report summarizes certain aspects of the authors' five-year research study on the effects of infertility on well-being, and the role of psychosocial factors in explaining these effects. The study was based on three rounds of interviews (1988, 1989, and 1990) of 275 married couples in southeastern Michigan. Members of 185 of these couples were infertile; members of the other 90 couples were presumed to be fertile.

The aspects of the study reviewed pertain to psychosocial responses to infertility; couples' behaviours, attitudes, and desires with respect to fertility and infertility; factors linked to infertile couples' subjective well-being; and changes in psychosocial factors associated with changes in parental status. In addition, the effects of intervening variables (e.g., coping skills, social support) on the effects of infertility stress are discussed.

The report also examines findings relating to satisfaction with infertility treatment; perceptions of the various intervention options, including adoption; and the effects of infertility on sexual satisfaction and timing of sexual intercourse.

Several conclusions arise from the findings of the study. For example, although couples were generally satisfied with their infertility treatment and rated their physicians' technical skills as the most important factor contributing to their satisfaction, they felt physicians should be more compassionate when delivering treatment. Since couples experienced less stress due to their infertility when they felt a sense of personal control and confidence that they would have a child, the report also recommends that health care providers should encourage, within realistic limits, such feelings in their patients.

The report recognizes the need for further research to determine the extent to which attitudes regarding various infertility interventions described in the study are representative of the general population. For example, both fertile and infertile couples in the study viewed interventions that allow only one member of the couple to be a biological parent of the child as less favourable; and, except for adoption, infertile couples were more favourable than fertile couples toward all interventions. The report suggests that these findings are relevant to acceptance of certain interventions and in judging the degree of emotional support couples may require to make an informed decision about the use of particular techniques. It might also be the case that infertile couples could benefit by having adoption addressed as a possible alternative from the onset of treatment.

The report also identifies a need for public education about the prevalence of infertility, the effects of age on one's fertility status, and the length of time one should realistically try to have a child before seeking the help of an infertility specialist.

Part 1. Introduction to the Study

Overview of this Report

This report summarizes selected results (some published and some unpublished) from a research study entitled "Life Quality, Psychosocial Factors and Infertility," which has been funded for the last five years by the U.S. National Institute of Child Health and Human Development. The basic purpose of this study was to examine the ways in which psychosocial factors affected infertile couples' life quality. First, the scope of the problem is described, followed by a brief review of the relevant infertility literature. Then the purposes of the U.S. study and its methodology are reviewed. Parts 2 through 5 describe some of the specific hypotheses that were tested and the results that were found. This study's data are still being analyzed; thus, this is a progress report.

Scope of the Problem

Approximately 8 percent of all U.S. married couples in which the woman is of childbearing age and is not contraceptively sterile are infertile; approximately 18 percent of U.S. married couples without children are

infertile (Mosher and Pratt 1990). Infertility is usually defined as the failure to conceive after one year of regular sexual intercourse without the use of contraceptives (Benson 1983). While about 50 percent of infertile couples eventually conceive and deliver, the other half will remain infertile (Collins et al. 1984).

The demand for infertility services has risen in recent years (Mosher and Pratt 1982). This is due to an improvement in the available medical technology and a possible increase in fertility problems that may be associated with delayed childbearing, sexually transmitted diseases, environmental exposure to toxins, or possibly an increased usage of intrauterine devices and abortions (Andrews 1984; Aral and Cates 1983).

Psychosocial Effects of Infertility: A Brief Review of the Literature

A number of investigators have documented the negative psychological and social effects of infertility on both members of a couple. Infertile couples experience a wide variety of negative emotions, including anxiety, fear, isolation, depression, guilt, frustration, and helplessness (Kirk 1963; Menning 1980; Rosenfeld and Mitchell 1979; Seibel and Taymor 1982). Members of infertile couples frequently report feeling inadequate, damaged, or defective as women or men. They often perceive their inability to reproduce as evidence that they are not physically whole and are a failure (Seibel and Taymor 1982). Infertile women have reported feeling as if they were "hollow," while infertile men have said they felt as if they were "shooting blanks" (Kirk 1963; Seibel and Taymor 1982). This diminished sense of femininity or masculinity reduces self-esteem and perceived physical attractiveness (Menning 1977). Infertile individuals feel helpless regarding an important component of their lives and identity that they had expected to be able to control (McCormick 1980).

Infertility places considerable stress on marital well-being. For approximately 70 percent of infertile couples, the infertility is due to only one partner (Benson 1983). The infertile individuals (the woman in approximately 40 percent of these couples and the man in 30 percent) frequently feel guilty and often tell their spouses it would be understandable if they wanted a divorce (Andrews 1984). Because of the stigma associated with infertility, members of infertile couples are frequently unwilling to confide in others (Miall 1985). Consequently, they must rely on their spouse for most of their emotional support (Menning 1977). While sometimes this can strengthen a relationship, it can also place a tremendous burden on it. Because each member of the couple is in crisis, it can be difficult for them to meet each other's needs. Also, if they are at different points of adjustment (for example, one is willing to consider adoption and the other is not), then conflict may arise over which strategies should be pursued (McGrade and Tolor 1981).

Sexual well-being is often damaged by infertility. Many infertile couples report perceiving sex as a chore rather than a pleasure (Seibel and

Taymor 1982). As one member of an infertile couple stated, "I feel like I must *produce* at a specified, clinical, predetermined moment, when the act of sharing love ... is something that should be spontaneous" (Menning 1977, 126). Members of infertile couples may feel guilty if they have sex too often, too seldom, or at the wrong times. Viewing sex as a homework assignment often produces impotence and a reduction in the frequency and enjoyability of sexual intercourse (Freeman et al. 1983; Menning 1977; Seibel and Taymor 1982).

In summary, infertility is a life crisis that reduces psychological well-being. Early research often concluded that the psychological problems evident in infertile couples had been the cause of their infertility (Eisner 1963). Recent work, however, acknowledges it is more likely that infertility produces psychological distress (Dunkel-Schetter and Lobel 1991; Seibel and Taymor 1982).

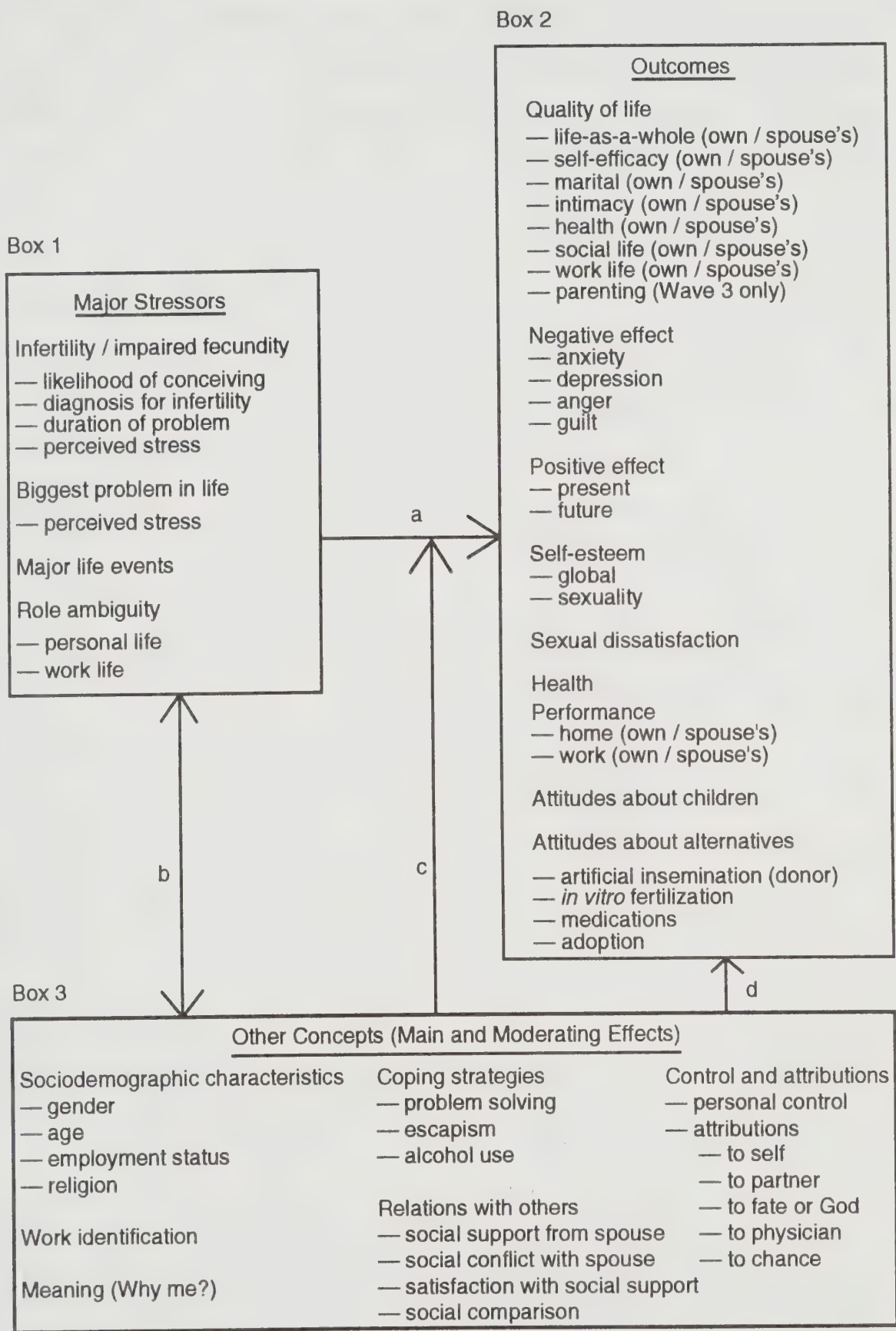
Many articles about the psychosocial effects of infertility have been based on the clinical impressions of physicians, nurses, social workers, and psychologists. The empirical studies that have been conducted typically have had small sample sizes and used a limited number of psychosocial measures. These reports provide important information; however, they rarely provide conclusive results.

Purpose of this Study

The purpose of the study described in this report was to test a number of hypotheses about the effects of infertility on well-being, and to examine the role of psychosocial factors in explaining these effects. Exhibit 1.1 presents the conceptual model that guided this research. In this study, infertility was conceptualized as a stressor (Box 1 of the exhibit). There is a large body of social-psychological research that has examined the impact of stress on people's psychological, social, and physical well-being. People under stress tend to experience reduced quality of life, increased negative affect, reduced self-esteem and performance, and more illness than people not undergoing stress (Avison and Turner 1988; Goldberger and Breznitz 1982; Holahan and Moos 1990; Pearlin et al. 1981). This hypothesized relationship is represented by path "a" connecting Box 1 and Box 2 of Exhibit 1.1. In this study, outcome variables related to attitudes about children and treatment alternatives were also included because of their relevance to infertile couples.

While a negative relationship has been found consistently between stress and well-being, the magnitude of this relationship is usually moderate. Thus, a number of authors have considered the mediating or moderating roles of psychosocial resources such as demographic characteristics, coping strategies, social relationships, and perceptions of control (Abbey and Andrews 1985; Fiore et al. 1983; Pearlin et al. 1981). Mediating effects — that is, the main effects from the mediating variables

Exhibit 1.1 Conceptual Model



— are exhibited in Exhibit 1.1 by paths “b” and “d,” which connect Box 3 with Boxes 1 and 2, respectively. These paths represent the hypothesis that individuals with psychosocial resources, such as good coping skills, will experience less stress (path “b”) and fewer negative outcomes (path “d”) than individuals who lack psychosocial resources. Moderating effects, that is, interaction effects, are represented by path “c,” which connects Box 3 with path “a.” This path represents the hypothesis that the strength of the relationship between stress and outcome depends on the level of the moderator variable.

Method of the U.S. Study

Study Participants

Separate in-person interviews were conducted with both wives and husbands in 275 couples (550 individuals) in 1988. Members of 185 of these couples were infertile; the members of the other 90 couples were presumed to be fertile. The infertile couples were principally recruited through infertility specialists. All but one of the major infertility practices in southeastern Michigan agreed to collaborate with this study. Eighty-one percent of the eligible nominees participated in the study ($n = 170$). Eligibility criteria were as follows: (1) married; (2) no previous children by either member of couple; (3) have not tried *in vitro* fertilization (IVF) or gamete intrafallopian transfer (GIFT); (4) white; and (5) middle-class (defined as having a high-school education and 1987 household income in the range of \$20 000 to \$100 000).

Only childless couples were included because the stress associated with infertility and the effect of becoming a parent may differ for couples with and without children. Patients who had tried IVF and GIFT were omitted because at the time these were considered “treatments of last resort” and, for the purposes of this study, patients who were relatively early in the treatment process were desired. White, middle-class couples were used because this is the sociodemographic profile of couples most likely to seek treatment for infertility (Henshaw and Orr 1987). The demographic profile of this study’s participants is also highly similar to that of zero parity women in the U.S. National Survey of Family Growth, which includes a representative sample of U.S. women of childbearing age (Mosher and Pratt 1990). Having a relatively homogeneous group of respondents allows more sophisticated analyses to be completed with a smaller number of cases.

Fifteen infertile couples were recruited from non-medical sources. Four couples came from RESOLVE (a self-help group for infertile individuals); five couples came from the Endometriosis Association (a self-help and information group); one couple was found through newspaper advertisements; one couple was referred by a study participant; and four couples were from marriage licence applicants.

At the initial interview, 87 percent ($n = 162$) of the infertile couples included in this study met the standard medical definition of infertility, which is one year of unprotected sexual intercourse without conceiving or without being able to carry a child to term. The remaining 23 couples had been trying to conceive a child for less than one year (seven months on average), but were being treated by an infertility specialist. Sometimes individuals with known physical problems related to infertility (e.g., endometriosis) or couples in which the woman is older than age 35 will seek and receive treatment before one year has elapsed.

A comparison group of 90 presumed-fertile couples was also included. These couples were required to have no known gynaecological or other problems associated with infertility, no children, and a desire to have children in a few years. Of these couples, 42 were recruited from gynaecological practices (many of the infertility specialists had a general practice or were affiliated with a general practice), 38 from marriage licence applicants, 5 from newspaper advertisements, and 5 from study participants' referrals.

Procedures

Patients who fit this study's eligibility criteria were asked by their physician if they were willing to participate in a university study of marriage, family, and childbearing issues. To supplement the sample, self-help group members were recruited through an article printed in their organization's monthly newsletter, and advertisements were placed in several local newspapers. Study participants were sent a letter asking if they knew of any eligible couples who would be interested in participating. Letters were also sent to a sample of the previous year's marriage licence applicants from the county in which most study participants lived, inviting them to participate.

Couples who agreed to participate were sent a brochure describing the study and were subsequently contacted by a professional interviewer from the Survey Research Center at the University of Michigan. At the initial interview (Wave 1), separate one-hour, in-person interviews were conducted with each member of the couple. Husbands and wives were usually interviewed on the same day and neither was able to hear the other's responses. The ethical guidelines of the American Psychological Association were followed throughout the study.

A follow-up telephone interview was conducted both one and two years later. At the second interview (Wave 2), 96 percent of the eligible couples were re-interviewed (265 couples). At the third interview (Wave 3), 97 percent of the eligible couples were successfully re-interviewed (263 couples). Only couples who were still married were eligible. Thus, 5 couples were ineligible for the third interview: one husband had died and 4 couples had divorced (2 infertile and 2 fertile couples). An additional 7 couples (6 infertile and 1 fertile couple) refused to be re-interviewed. By the second follow-up, another 5 couples had divorced (2 infertile and 3 fertile

couples). Because of this study’s focus on couples, individuals who had become divorced were not included in most analyses.

Although the words “infertile” and “infertility” are used in this paper, these words were not used with the couples who participated in the research. Pilot testing indicated that the term “infertile” connoted a sense of finality that the study participants found unsettling. Instead, in the interview the term “fertility problem” was used.

Descriptive Profile of Study Participants at the Initial Interview

Exhibit 1.2 provides some descriptive information about the study participants. At the initial interview, the infertile women interviewed for this study ranged in age from 22 to 42; the mean age was 32 years. The infertile men ranged in age from 23 to 44; the mean age was 34 years. The mean number of years infertile couples had been married was six. At the initial interview, presumed-fertile women ranged in age from 18 to 37; the mean age was 28 years. Presumed-fertile men ranged in age from 22 to 46; their mean age was 30. The mean number of years presumed-fertile couples had been married was two.

Exhibit 1.2 Demographic Characteristics

	Fertile respondents		Infertile respondents	
	Men (n = 90)	Women (n = 90)	Men (n = 185)	Women (n = 185)
Mean age	30 yr	28 yr	34 yr	32 yr
Mean length of marriage	2 yr	2 yr	6 yr	6 yr
Mean length of time trying to have a child	X ¹	X ¹	30 mo	32 mo
Approximate median annual income	\$49 700	\$46 700	\$55 700	\$55 100
Mean education	3 yr college	3 yr college	3 yr college	3 yr college
Active member of labour force	100%	96%	98%	93%

¹ not assessed/not relevant

It is not surprising that married couples who had not yet tried to have a child were younger and had been married for a shorter time than couples who were actively trying to have a child. The infertile couples had been trying to have a child for about 31 months on average (men reported 30 months and women reported 32 months). Age and number of years married were included in a number of preliminary analyses. In virtually all

cases, these variables were not significantly correlated with the psychosocial concepts examined in this study, and their inclusion in multivariate analyses did not change the results.

At the initial interview, the average annual household income reported by infertile couples was about \$55 000. The presumed-fertile couples reported an average annual household income of about \$48 000 (women's and men's responses differed slightly). Members of infertile and presumed-fertile couples averaged three years of college education. Ninety-eight percent of the infertile men and 93 percent of the infertile women were active members of the workforce. One hundred percent of the presumed-fertile men and 96 percent of the presumed-fertile women were active members of the workforce.

Religious preference was also highly similar among the infertile and fertile couples. Approximately 40 percent of the men were Catholic, 30 percent were Protestant, 7 percent were Jewish, 20 percent had no religious preference, and the remainder had another religious preference. Approximately 46 percent of the women were Catholic, 35 percent were Protestant, 6 percent were Jewish, 11 percent had no religious preference, and the remainder had another religious preference. Both infertile and presumed-fertile men were somewhat more likely than women to state that they had no religious preference.

Based on study participants' self-reports, 46 percent of the couples' infertility problems were due to female factors, 10 percent to male factors, 30 percent to a combination of male and female factors, and 14 percent to unexplained factors. This is a lower rate of male factors than appears to exist in the general population (Benson 1983).

Parental Status at the Third Interview

By the two-year follow-up interview, 73 (42 percent) of the infertile couples were parents. (One additional couple had twins who died at birth; they are not considered parents for the purposes of this paper.) Fifty-nine of these couples had become parents through the wives' pregnancy, while 14 couples had adopted an infant. Six of the couples had had multiple births (five sets of twins and one set of triplets, although only one of the triplets survived). The children who were born through the wives' pregnancy ranged in age from 3 to 18 months of age; the mean age was 10 months. Adopted children ranged in age from 5 to 30 months; the mean age was 16 months. Six couples already had a second child. One of the couples who had adopted their first child had a second child through the wife's pregnancy.

Twenty-seven (36 percent) of the presumed-fertile couples were parents by the two-year follow-up interview. None of these births involved adoption, multiple births, or intervention from a specialist. These children ranged in age from 1 to 17 months of age; the median age was 9 months. One of these couples already had a second child.

Ten of the original presumed-fertile couples developed a fertility problem during the course of the study. One of these couples bore a child prior to the third interview, while the other nine couples were still trying to have a child. The remaining presumed-fertile couples either had not yet tried to have a child or had been trying for only a few months.

Measures

Exhibit 1.3 provides a summary of most of the scales used in this study. Multiple-item scales were used to assess most of the concepts included in Exhibit 1.1. Whenever possible, the scales used in this study were based on previous research. For most scales, to keep the interview to one hour, it was necessary to select only a subset of the original scale's items. For some of the concepts of interest, no measures could be found in the literature, so the research team developed a measure. The internal consistency reliability of these scales was measured using Cronbach alpha. With only a few exceptions, Cronbach alphas were within an acceptable range (> 0.70).

Detailed information about question wording is provided in the present authors' articles listed in the Bibliography. However, since the measure of "fertility-problem or biggest-problem stress" developed by the research team is referred to in many of the papers, it is described here. A series of nine questions assessed the amount of stress and disruption the fertility problem had produced overall and in various domains of study participants' lives during the last 12 months: three items assessed overall stress (experienced disruption, life change, and stress); the other six items referred to specific life domains (physical health, mental health, marriage, sex life, finances, relations with others). These domains were selected based on previous research and pilot interviews with infertile couples. Members of presumed-fertile couples (and infertile couples who were parents at the follow-up interviews) were asked the same series of items in terms of the biggest problem in their lives.

Exhibit 1.3 Major Scales Constructed and Their Reliabilities

Concept	Source	Cronbach alpha			
		Wave 1	Wave 2	Wave 3*	
<i>Stressors</i>					
Fertility problem (FP) stress	Research team	0.88	0.88 ^c	0.88 ^e	
Biggest problem (BP) stress	Research team	0.80	0.85	0.84	
FP/BP stress	Research team	?	0.86	0.85	
Major life events	Based on Sarason et al. (1978)	NA	NA	NA	
Home life role ambiguity	Based on Caplan et al. (1984)	0.67	0.61	0.70	

Exhibit 1.3 (*cont'd*)

Concept	Source	Cronbach alpha		
		Wave 1	Wave 2	Wave 3*
Work life role ambiguity	Based on Caplan et al. (1984)	0.74	NM	NM
Perceived stress	Subset of Cohen et al. (1983)	NM	NM	0.75
Adoption/parenting/ pregnancy stress	Research team	NM	NM	0.76
<i>Outcomes</i>				
Quality of life:				
Global (own)	Based on Andrews and Withey (1976)	0.74	0.74	0.78
Self-efficacy (own)	Based on Andrews and Withey (1976)	0.60	0.57	0.60
Marriage (own)	Based on Andrews and Withey (1976)	0.85	0.90	0.92
Intimacy (own)	Based on Andrews and Withey (1976)	0.83	0.85	0.86
Health (own)	Based on Andrews and Withey (1976)	0.66	0.68	0.66
Global (spouse's)	Based on Andrews and Withey (1976)	0.76	NM	NM
Self-efficacy (spouse's)	Based on Andrews and Withey (1976)	0.68	NM	NM
Marriage (spouse's)	Based on Andrews and Withey (1976)	0.84	NM	NM
Intimacy (spouse's)	Based on Andrews and Withey (1976)	0.85	NM	NM
Health (spouse's)	Based on Andrews and Withey (1976)	0.79	NM	NM
Child #1	Research team	NM	NM	0.80 ^g
Child #2	Research team	NM	NM	0.68 ^g
Affect:				
Depression	Based on Derogatis et al. (1974)	0.69	0.74	0.69
Anxiety	Based on Derogatis et al. (1974)	0.61	0.64	0.64

Exhibit 1.3 (*cont'd*)

Concept	Source	Cronbach alpha		
		Wave 1	Wave 2	Wave 3*
Guilt	Research team	SI	SI	SI
Anger	Based on Caplan et al. (1984)	0.65	0.72	0.75
Positive, present	Research team	0.72	0.74	0.82
Positive, future	Research team	0.67	0.69	0.70
Performance:				
Home life (own)	Based on Caplan et al. (1984)	0.86	0.88	0.85
Work life (own)	Based on Caplan et al. (1984)	0.80	NM	NM
Home life (spouse's)	Based on Caplan et al. (1984)	0.89	NM	NM
Self-esteem	Rosenberg (1965)	0.76	0.77	0.76
Sexual self-esteem	Research team	0.61	0.69	0.71
Sexual dissatisfaction	Research team	0.82	0.84	0.85
Marital conflict	Research team	0.65 ^d	0.69 ^d	0.67 ^d
Importance of children	Research team	0.75	0.79	0.80
Attitudes about parenting	Research team	NM	0.51	0.51
Good child #1	Based on Little and Thompson (1983)	NM	NM	0.74 ⁱ
Good child #2	Based on Little and Thompson (1983)	NM	NM	0.83 ⁱ
Attitudes about fertility treatment				
Use of AIH ¹ /IVF	Research team	0.74	NM	0.74
Use of donors/surrogates	Research team	0.86	NM	0.85
Use of medications	Research team	0.79	NM	0.78
Own health	Based on Derogatis et al. (1974)	0.60	0.66	0.63
<i>Moderator variables</i>				
Personal control	Based on Abbey and Andrews (1985)	0.79	0.81	0.80
Control over solution to FP	Research team	0.82	0.84	0.88

Exhibit 1.3 (*cont'd*)

Concept	Source	Cronbach alpha		
		Wave 1	Wave 2	Wave 3*
Work identification	Research team	0.68	0.72	0.71
Meaning	Based on Abbey (1987)	0.75	0.84 ^a	0.78 ^f
Social relationships:				
Satisfaction with social support	Sarason et al. (1983)	0.82	0.81	0.85
Affirmation social support from spouse	Based on Abbey and Andrews (1985)	0.79	0.84	0.85
Affirmation social support to spouse	Based on Abbey and Andrews (1985)	0.77	NM	0.79 ^h
Esteem social support from spouse	Based on Abbey and Andrews (1985)	0.79	0.86	0.86
Esteem social support to spouse	Based on Abbey and Andrews (1985)	0.80	NM	0.86 ^h
Disapproval from spouse	Based on Abbey and Andrews (1985)	0.70	0.74	0.80
Disapproval to spouse	Based on Abbey and Andrews (1985)	0.69	NM	0.71 ^h
Negative affect from spouse	Based on Abbey and Andrews (1985)	0.75	0.80	0.81
Negative affect to spouse	Based on Abbey and Andrews (1985)	0.76	NM	0.78 ^h
Coping:				
Problem solving	Based on Folkman and Lazarus (1985)	0.62	0.74 ^b	0.72 ^b
Escape	Based on Folkman and Lazarus (1985)	0.69	0.68	0.72

* Waves 1, 2, and 3 correspond to the first, second, and third interviews, respectively.

NM = not measured at this wave

SI = no alpha because just a single item

NA = items not suitable for alpha calculation

¹AIH = artificial insemination with husband's sperm

a Based on only 24 new fertility problem cases at Wave 2.

b The Wave 2 and 3 index of problem-solving coping includes an additional item beyond those available for Wave 1.

c When only 9 items are included, alphas at Waves 1, 2, and 3 are 0.86, 0.88, and 0.88.

Exhibit 1.3 (*cont'd*)

- d These alphas are for all respondents combined. For respondents with fertility problems, alphas at Waves 1, 2, and 3 are 0.66, 0.74, and 0.67; for respondents who reported on another problem, alpha is 0.66 at Wave 2 and 0.67 at Wave 3 (alpha was not calculated at Wave 1).
- e Item M6 (stress of keeping track of when ovulating) asked only of newly infertile couples ($n = 24$).
- f At Wave 3 this was asked of anyone who had ever had a fertility problem ($n = 325$).
- g Both Child #1 and Child #2 share the item.
- h Included in Home Questionnaire ($n = 459$).
- i Included in Home Questionnaire; parallel items for 2 children ($n = 177, 27$).

Part 2. Selected Psychosocial Responses to Infertility

Gender Differences in Response to Infertility*

Introduction

A number of authors have found that infertility is more stressful for women than for men (Andrews 1984; Miall 1985; Newton, et al. 1990; Wright et al. 1991). While parenting is a central component of society's expectations for both women and men, traditionally motherhood is perceived as the central role for women, and paid employment the central role for men. Many infertile women state they cannot imagine a life without children, while their husbands express less concern (Mahlstedt 1985). Also, regardless of which member of the couple has the physical problems producing infertility, since the majority of tests and treatments focus on the woman's body, it is she who must forego her time and bear the physical burden involved. Other people often assume that infertility is due to a problem in the woman (Andrews 1984), and this adds to the stress she experiences.

The purpose of this set of data analyses was to examine gender differences in response to infertility in the 1988 set of data. Because a comparison group of presumed-fertile couples was available, it could be determined if any gender differences found during this phase of the study were unique to the infertility experience, or were also found among the comparison couples.

* This is a summary of Abbey et al. (1991a).

Results

Exhibit 2A.1 presents the findings from a series of paired *t*-tests in which husbands' and wives' responses were compared. Considering first the differences found only among infertile couples, infertile wives experienced greater fertility-problem stress than did their husbands. In contrast, infertile husbands experienced more home life stress than did their wives. Both women and men agreed that home life performance was better for wives than husbands.

Infertile women also engaged in more problem-solving coping than did their husbands. Infertile wives felt more responsible for the fertility problem than did their husbands. Even when the source of the infertility problem was controlled for, women who were the sole physiological source of the couple's infertility felt more responsible than did men who were the sole physiological source of the couple's infertility. Infertile husbands felt that chance factors were more responsible for their fertility problem than did their wives. Infertile wives perceived themselves as having more control over the solution to the problem than did infertile men. Thus, infertile women felt more responsibility and control than did their husbands.

Infertile husbands were more satisfied than their wives with the meaning they had found in their infertility and, more than their wives, they felt they had learned from the experience. Infertile wives felt that having children was more important than did infertile husbands.

A number of gender differences were found for both the infertile and the presumed-fertile couples. Women in both groups had lower self-esteem and higher sexual dissatisfaction than did their husbands. Both groups of women also reported experiencing more depression and using more escape coping than did their husbands. Both infertile and presumed-fertile women were more satisfied with their network social support than were their husbands, while both infertile and presumed-fertile husbands experienced more interpersonal conflict with their spouse than did wives. Finally, both infertile and presumed-fertile men were more confident than their wives that someday they would have a child biologically related to them and their spouse.

It is also important to note that for some concepts in Exhibit 2A.1 no gender differences were found for either infertile or presumed-fertile couples. Levels of global and marital life quality and spouse support did not differ for women and men. Despite the differences in stress, negative affect, coping, and performance described above, men and women had comparable levels of life satisfaction.

Exhibit 2A.1 Comparison of Mean Scores for Wives and Husbands Separately for Infertile and Presumed-Fertile Couples

	Infertile couples				Presumed-fertile couples					
	Wives		Husbands		Paired t-tests	Wives		Husbands		
	M	(SD)	M	(SD)		M	(SD)	M	(SD)	
<i>Stress</i>										
Fertility/biggest problem										
Stress	2.54	(0.73)	2.13	(0.70)	-6.88***	2.29	(0.71)	2.22	(0.62)	n.s.
Home life stress	1.81	(0.76)	2.09	(0.77)	3.93***	1.98	(0.88)	1.89	(0.63)	n.s.
<i>Performance</i>										
Respondent's home performance	3.86	(0.69)	3.64	(0.75)	-3.31**	3.74	(0.76)	3.77	(0.71)	n.s.
Spouse's home performance	3.80	(0.86)	4.22	(0.63)	5.81***	3.79	(0.83)	4.20	(0.68)	3.94***
<i>Well-being</i>										
Self-esteem	4.15	(0.54)	4.26	(0.56)	2.28*	4.19	(0.55)	4.42	(0.44)	3.11**
Sexual dissatisfaction	2.11	(0.66)	1.93	(0.83)	-2.66**	2.12	(0.78)	1.84	(0.67)	-2.87**
Global life quality	3.16	(0.68)	3.25	(0.62)	n.s.	3.31	(0.54)	3.37	(0.54)	n.s.
Marital life quality	4.72	(0.55)	4.68	(0.61)	n.s.	4.60	(0.71)	4.68	(0.62)	n.s.
Depression	2.00	(0.69)	1.78	(0.63)	-3.63***	1.84	(0.46)	1.57	(0.58)	-3.52***
<i>Coping</i>										
Problem-solving	2.76	(0.59)	2.38	(0.61)	-6.35***	2.47	(0.53)	2.37	(0.54)	n.s.
Escape	2.77	(0.75)	2.14	(0.69)	-9.14**	2.33	(0.65)	2.09	(0.71)	-2.23*

Exhibit 2A.1 (cont'd)

	Infertile couples				Paired t-tests	Presumed-fertile couples				
	Wives		Husbands			Wives		Husbands		
	M	(SD)	M	(SD)		M	(SD)	M	(SD)	
<i>Support and conflict</i>										
Satisfaction with support network	4.37	(0.64)	4.09	(0.71)	-4.38***	4.36	(0.71)	4.17	(0.67)	-2.38*
Spouse support	4.25	(0.66)	4.15	(0.65)	n.s.	4.27	(0.58)	4.14	(0.67)	n.s.
Spouse conflict	1.59	(0.52)	1.79	(0.58)	4.35***	1.66	(0.52)	1.79	(0.50)	2.01*
<i>Attributions</i>										
Self	2.78	(1.36)	2.34	(1.19)	-3.19**	3.03	(1.20)	3.34	(1.41)	n.s.
Spouse	1.93	(1.11)	2.61	(1.29)	4.90***	2.31	(1.16)	1.93	(1.40)	n.s.
Chance	2.11	(1.12)	2.45	(1.31)	3.11***	1.59	(1.02)	1.70	(0.82)	n.s.
<i>Perceived control over solution to problem</i>										
Self	3.12	(1.19)	2.85	(1.08)	-2.18*	3.59	(1.12)	3.85	(1.12)	n.s.
Spouse	2.74	(1.19)	3.03	(1.20)	2.17*	3.01	(1.42)	2.93	(1.34)	n.s.
<i>Satisfied with meaning found in event</i>										
Positive learning experience	2.86	(0.94)	3.25	(0.76)	3.17**	3.36	(0.65)	3.28	(0.79)	n.s.
	1.98	(0.72)	2.24	(0.74)	4.13***	2.17	(0.78)	2.32	(0.66)	n.s.

Summary

Infertile women experienced more stress associated with their infertility than did men. Women desired a child more than their husbands did, yet felt less confident they would have one. Women engaged in more problem-solving and escape-oriented coping and found less meaning in their experience than did men. For women, infertility seems to be more central to their lives and more frequently on their minds. As one infertile woman stated, "The infertility is always there, casting a shadow over everything in my life."

Infertile men experienced greater home life stress and poorer home life performance as compared to their wives. Men experienced more interpersonal conflict and less perceived control. Thus, women fared worse in regard to infertility-related aspects of life, while men fared worse in general aspects of home and marital life. As one infertile man said, "It's not that big a deal to me ... but my wife doesn't feel that way and that makes it difficult."

Some of the differences found between infertile women and men were also found between presumed-fertile women and men. These differences were mostly in the expression of negative affect and social support, findings that have been reported in previous research (Diener 1984; Spence et al. 1985). These results serve as an important reminder that some responses to infertility are similar to responses to other types of life crises, and some of the gender differences found in studies relating to infertility reflect general gender differences in response to stress. This conclusion does not minimize the negative impact gender differences may have on infertile couples' ability to communicate with each other and maintain high levels of marital satisfaction; it simply puts these gender differences in a broader context.

Satisfaction with Infertility Treatment

Introduction

Examination of the three sets of data collection show some of the preliminary results obtained by examining infertile couples' satisfaction with their infertility treatment. We established a variable known as parental status, which measured parental status at the time of the third interview conducted in 1990. Infertile couples fell into one of five groups: those who had had a live birth by either interview two or interview three; those who had adopted by either interview two or interview three; those who were pregnant at the time of the third interview; those who were still trying to have a child and were not pregnant at the time of the third interview; and those who had given up trying to have a child by the third interview. These categories are used in the four exhibits described below.

Results

Exhibit 2B.1 depicts the cumulative number of tests received over the three sets of data collection. Exhibit 2B.1 shows that women consistently had more tests than men. This was expected, since the literature states that women receive most of the tests and treatments; this exhibit further supports the representativeness of our sample. Those women who adopted, who were pregnant, or who were still trying to have a child received the most tests; those with a live birth had received the fewest tests. This may be showing that the majority of women who are successful and have a live birth do so relatively early in their treatment, causing fewer tests to be performed, and/or they may have a more easily diagnosed and treated problem.

Exhibit 2B.1 Cumulative Number of Tests for Married Couples with Primary Infertility in Southeastern Michigan, 1988-1990

Parental status in 1990	Men		Women	
	Range	\bar{X}	Range	\bar{X}
Live birth (n = 61)	0-10	2.5	0-30	7.0
Adoption (n = 14)	1-11	6.1	0-40	15.4
Pregnant (n = 9)	1-12	3.9	2-41	14.9
Still trying to have a child (n = 85)	0-19	5.9	0-48	15.9
Gave up trying to have a child (n = 15)	0-11	4.2	4-34	11.7

Exhibit 2B.2 shows husbands' and wives' satisfaction with infertility treatment. Couples were told, "We want to find out how you feel about the professional treatment you have received for your fertility problem. Overall, how would you say you feel?" Scores ran from 1, which reflected they were very satisfied with the treatment they received, to 5, which reflected they were very dissatisfied with the treatment they received. Although there is variation at the second interview among the five parental status groups, the sample sizes are small for those who had a live birth, adopted, or were pregnant.

Overall, wives and husbands were relatively similar in their satisfaction with treatment. There was not much change for husbands and wives who were still trying to have a child between the second and third interviews, with both being somewhat satisfied. Those people who gave up trying between the second and third interviews showed more satisfaction with treatment, but the sample size dropped at the third interview, which again does not lend much support to the direction of the change.

Exhibit 2B.2 Satisfaction with Infertility Treatments* for Married Couples in Southeastern Michigan, 1989, 1990

Mean scores	Wave 2		Wave 3	
	Husbands	Wives	Husbands	Wives
Live birth	3.0 (4) ¹	2.8 (5)	n.a.	n.a.
Adoption	1.9 (8) ¹	1.7 (8)	n.a.	n.a.
Pregnant	2.1 (8) ¹	2.0 (9)	n.a.	n.a.
Still trying to have a child	2.6 (73) ¹	2.2 (73)	2.4 (78)	2.3 (81)
Gave up trying to have a child	2.5 (10) ¹	2.4 (13)	1.0 (2)	1.0 (2)

* Scores ran from 1 = very satisfied to 5 = very dissatisfied.

n.a. = not applicable

¹numbers in parenthesis = n, the sample size for that group

Exhibit 2B.3 contains explanations for men's and women's satisfaction or dissatisfaction with infertility treatment. Respondents were specifically asked, "Can you briefly tell me why you answered that way?" in response to the previous question about the ranking of their satisfaction with treatment. Respondents were allowed to make multiple mentions. The responses reflect those people who were still trying to have a child at the third interview (Wave 3). Both men and women showed the same hierarchy of responses, rating technical skills as their highest consideration. Emotional responses of the physician (e.g., "my doctor cares about me," "... is warm, calm, supportive;" or on the negative side, "my doctor is insensitive," "... lacks compassion," "... pays more attention to my spouse than to me") rated second but were stated by considerably fewer respondents — i.e., 27 percent compared to the 89 percent of men stating technical skills as the highest consideration in their rating. Trust in physician was rated as one of the lowest explanations. This shows that the technical skills of their physician are very important in determining satisfaction with treatment.

Exhibit 2B.3 Explanations for Satisfaction or Dissatisfaction with Infertility Treatment Among Married Couples with Primary Infertility in Southeastern Michigan, 1990

Explanation	Men (n = 81) %	Women (n = 83) %
Technical skills	89*	76
Emotional responses	27	42
Office staff	19	22
Information provided	16	17
Trust in physician	4	2
Provision of counselling or referral to such	1	1

* Multiple mentions allowed.

Exhibit 2B.4 contains infertile men's and women's responses to the open-ended question, "Given all that you have experienced in your attempts to have a child, either by birth or through adoption, what would you do differently if you could turn back the clock and start all over?" In this exhibit every respondent who had ever had an infertility problem was included. Again, men and women were quite similar in their responses. One woman stated, "My husband goes through all the phases I do, but not necessarily at the same time." The top three responses for men and women were: they would have started trying earlier, would have started treatment earlier, and would have done nothing differently. Of these responses, men were most apt to say they would have done nothing differently; women were more apt to say they would have started trying to have a child earlier. The remaining seven responses were roughly ranked the same for both men and women, although 13 percent of the women and 7 percent of the men said they would have looked into adoption earlier.

Preliminary analysis of predictors of patient satisfaction with infertility treatment included examining variables that had previously shown association with fertility-problem stress. These included such areas as the number of infertility tests and infertility treatments received, household income, personal control, the importance of children to a person, fertility-problem stress, satisfaction with social support received from one's network of friends, the length of time respondents perceived they had been trying to have a child, how much respondents held themselves responsible for the fertility problem, and the acceptability of prescribed treatment to an individual. Of these variables, personal control was the only one to show

significant association, and this was a rather low association. More analyses need to be completed before any results can be meaningful.

Exhibit 2B.4 Changes that Married Couples with Primary Infertility in Southeastern Michigan Would Make in Their Infertility Treatment During 1990

	Men (n = 157) %		Women (n = 163) %
1. Nothing different	35*	1. Started trying earlier	34
2. Started trying earlier	32	2. Started treatment earlier	23
3. Started treatment earlier	17	3. Nothing different	21
4. Personal change	9	4. Looked into adoption earlier	13
5. Looked into adoption earlier	7	5. Personal change	10
6. Seen a different physician	4	6. Seen a different physician	8
7. Used a different treatment earlier	3	7. Used a different treatment earlier	3
8. Not sought treatment	2	8. Not sought treatment	4
9. Sought more information	2	9. Sought more information	1
10. Sought support from family, friends earlier	1	10. Sought support from family, friends earlier	1

* Multiple mentions allowed.

Summary

In summary, infertile couples are generally satisfied with the infertility treatment they receive, they rate their physicians' technical skills as the most important factor contributing to their satisfaction or dissatisfaction with treatment, and they would advise their physicians to be more compassionate when delivering treatment. Although about one-third of the men would have done nothing differently in their infertility treatment, about a third of the infertile women would have started trying to have a child earlier. These responses tell us that people need to be more educated about infertility — specifically the prevalence of it, the need to recognize the

effects of age on one's fertility status, and how long a person should realistically try to have a child before seeking the help of an infertility specialist.

Advice to Physicians

Introduction

Study participants who were still trying to have a child, who had given up trying to have a child, or who were new fertility-problem couples in 1990 were asked what advice they would give to physicians who treat patients with fertility problems. Participants' open-ended responses to this question were summarized in several major categories, which are described below.

Results

Exhibit 2C.1 shows the advice infertile men and women would give to physicians who treat patients with fertility problems. Men and women rated the highest four categories the same:

- (1) both men and women advised infertility specialists to be compassionate, which was the most frequently mentioned response to this open-ended question, given by 40 percent of the men and 48 percent of the women;
- (2) information-sharing, such as explaining options or treatment plans better or taking the time to ask or answer questions, was rated second, with 26 percent of the men and 36 percent of the women giving this advice;
- (3) "improve office staff operations" was the advice given by 14 percent of the men and 17 percent of the women; and
- (4) "use more effective treatment" was advised by 12 percent of the men and 15 percent of the women.

In addition, 11 percent of the women wanted the infertility specialist to spend more time with them, whereas 5 percent of the men gave this advice. One notable difference between men and women was that 5 percent of the women advised infertility specialists to provide referrals to a support group for their patients, while none of the men gave this advice.

As noted, the second most commonly mentioned advice was to share information with patients. Examination of the questionnaires of the people giving this response raises questions concerning the informed consent experienced by some of the respondents in this study. The most common specific complaint was that physicians needed to explain the plan of treatment to the individual patient. Respondents said such things as:

- "Be freer with information"; "Let people know what [the physicians] plan on doing";
- "Set up a plan of action and let the patient know what it is beforehand";

- “Give an overview of procedures and what is going to be done”;
- “Be sure the patient understands what you are prescribing and what the long term plan is”; and
- “Be more explicit — let [the patient] know *exactly* what is going on — leave no doubts.”

Exhibit 2C.1 Advice to Infertility Specialists from Married Couples in Southeastern Michigan, 1990

	Men (n = 77) %		Women (n = 81) %
1. Need to be compassionate	40*	1. Need to be compassionate	48
2. Share information	26	2. Share information	36
3. Improve office staff operations	14	3. Improve office staff operations	17
4. Use more effective treatment	12	4. Use more effective treatment	15
5. Be honest, open	12	5. Spend more time with patient	11
6. Nothing different	10	6. Be honest, open	7
7. Respect individual differences	9	7. Nothing different	6
8. Spend more time with patient	5	8. Respect individual differences	5
9. Include both spouses	5	9. Include both spouses	5
10. Tell patient when to stop treatment	4	10. Refer to support group	5
		11. Tell patient when to stop treatment	1

* Multiple mentions allowed.

The second specific complaint with regard to information-sharing was that respondents wanted to have all the available options, including adoption, explained to them. One respondent said, "Give the patient all possibilities and alternatives, such as adoption." Several other specific suggestions included, "use layman's terms," "ask questions of patients to see if they understand," "review risks involved," "prepare patients for lack of success," "give reasonable expectations," and "involve nurses in information-sharing."

Summary

Infertile couples had a variety of advice to give to physicians. The types of advice provided by men and women were quite similar. The most frequently mentioned forms of advice were showing compassion, providing accurate and detailed information, and improving office staff operations. These findings suggest that infertile patients are sensitive to how they are treated by health care personnel, and indicate specific ways in which physician-patient relations can be improved.

Predictors of the Stress Associated with Infertility*

Introduction

While infertility is stressful for most women and men, it is clear from the literature that infertility is more upsetting for some individuals than for others (Daniluk 1988; Freeman et al. 1985). Social psychological research on stress and coping can help explain these individual differences. As Folkman et al. (1979) described, cognitive appraisal of a stressor moderates the relationship between an event and the stress associated with that event. Individuals ask themselves the question, "Am I in trouble?" and their answer to that question determines whether the event is perceived as benign or harmful. Stress should be high only when the situation is perceived as harmful and the individual does not believe that she or he has sufficient resources to handle the stressor.

The purpose of the analyses described below was to examine the relationships between a variety of different demographic, treatment, psychological, and social factors, and infertile couples' perceived fertility-problem stress. The data for women and men were analyzed separately so that gender differences in the predictors of stress could be considered. These analyses use cross-sectional data, so the causal ordering among these concepts cannot be determined.

Results

Pearson product moment correlation coefficients are presented in Exhibit 2D.1. Looking first at the demographic variables, both age and number of years married were unassociated with fertility-problem stress. This finding was unexpected; we had hypothesized that age and number of

* This is a summary of Abbey et al. (1992b).

years married would be positively related to experienced stress — that is, that older and longer-married respondents would experience significantly more stress.

Exhibit 2D.1 Correlations Between Fertility-Problem Stress and Psychosocial Variables Separately for Women and Men

Fertility-problem stress and:	Women	Men
Age	0.02	0.04
No. of years married	0.03	0.07
Income	-0.04	-0.21*
Past treatment costs	0.24*	0.19*
Anticipated future treatment costs	0.17	0.29**
How long trying to have a child	0.02	0.10
No. of physicians seen	0.15	0.23*
No. of tests received	0.32**	0.26**
No. of treatments received	0.23*	0.26**
Attitudes about infertility treatments (AID and surrogacy)	-0.24*	-0.10
Confidence one will have a child	-0.27**	-0.33**
Importance of children	0.24*	0.11
Perceived personal control	-0.52**	-0.41**
Attributions of responsibility to self	0.07	0.19*
Attributions of responsibility to spouse	0.03	-0.10
Attributions of responsibility to physicians	0.23*	0.18
Satisfaction with network social support	-0.30**	-0.17

* $p < 0.05$

** $p < 0.01$

AID = artificial insemination with donor sperm

Source: A. Abbey, L.J. Halman, and F.M. Andrews. "Psychosocial, Treatment, and Demographic Predictors of the Stress Associated with Infertility." *Fertility and Sterility* 57 (1992), 126. Reproduced with permission of the publisher, the American Fertility Society.

Income was significantly negatively correlated with stress for men only — that is, the lower the couple's income, the more fertility-problem stress the husband experienced, possibly out of concern they would not be able to afford the required tests and treatments.

Treatment costs and number of tests and treatments received were significantly positively correlated with fertility-problem stress for both women and men. Number of physicians seen was significantly positively correlated with stress for men only (although there was a similar trend for women). The more positive women felt about infertility treatments that involved artificial insemination with donor sperm (AID) or surrogacy, the less stress they experienced.

Confidence that one will have a child and a sense of personal control were significantly negatively related to fertility-problem stress for both men and women. The importance of children to the individual was significantly positively correlated with stress for women. Attributions of responsibility to the self were significantly positively related to stress for men, while attributions of responsibility to physicians were significantly positively related to stress for women. The more satisfied women were with their network social support, the less stress they experienced (there was a similar trend for men).

When these various predictors were examined using multiple regression, it was found that personal control, confidence one will have a child, the importance of children, number of tests received, and attributions of responsibility to physicians were all significant predictors of women's fertility-problem stress. For men, personal control, confidence one will have a child, number of physicians seen, future treatment costs, and income were significant predictors of fertility-problem stress. For both women and men, more than 35 percent of the variance in fertility-problem stress was explained with this set of predictors.

Summary

For both women and men, the greater their confidence that they would have a child and the greater their perceived personal control, the less stress they experienced due to their infertility. This finding suggests that health care providers should encourage, within realistic limits, such feelings in their patients.

Men's traditional, societal responsibility for wage earning may explain the stronger relationship between the factors of income, number of physicians seen (each of whom presents a bill), and anticipated treatment costs, and men's fertility-problem stress, as compared to women's. Despite the fact that almost all of the infertile women in this study worked for pay, their husbands may feel more responsible for the couple's finances, and thus may feel greater stress when their income seems less than necessary to cover anticipated treatment costs.

Women, who received many more tests and treatments than did their husbands, also were more stressed by them. Women reported feeling stress if the physician observed they failed to keep up their temperature charts or have intercourse on the appropriate days. The medical focus on the woman's body may help explain why attributions of responsibility to the physician were a significant predictor of women's (but not men's) fertility-

problem stress. Women's frequent contacts with and reliance on physicians may create dissatisfaction with the quality of care received, thus leading women to hold the physicians partially responsible for the problem. While such responses may seem illogical to physicians, they signal that the patient's current stress level is high and that she may need a respite from the aspects of treatment that she finds most upsetting.

Part 3. Couples' Behaviours, Attitudes, and Desires with Respect to Fertility and Infertility

Favourability Toward Infertility Interventions*

Introduction

Individual members of couples were asked, "People have different opinions about various methods for having a child. Please tell me how you feel about the possibility of your using each of the following methods, if it were needed." The 11 infertility interventions measured included artificial insemination with the husband's sperm (AIH), artificial insemination with a donor's sperm (AID), artificial insemination using both the husband's and a donor's sperm mixed together (AIH&D), hormones used to stimulate ovulation in women, hormones used to increase the sperm count in men, progesterone (a specific hormone) vaginal suppositories used to help support a pregnancy, tying the cervix to prevent premature dilation of the cervix, *in vitro* fertilization (IVF), adoption, surrogate mother with husband-donated sperm and wife-donated ova (S/W), and surrogate mother with husband-donated sperm and the surrogate's ovum (S/S). Attitudes were measured on 5-point Likert-type scales with options ranging from (1), strongly opposed to personal use of a particular intervention, to (5), strongly in favour of personal use of a particular method.

We also examined the interventions and procedures the fertility-problem couples had received at the time of the interview. The most frequent intervention used for women was the prescription of medications to stimulate ovulation. Adoption was currently or had been previously considered by 20 percent of all fertility-problem couples and was the most commonly mentioned intervention by men. Endometriosis was a relatively common problem for the female respondents, with 19 percent stating they had had or were scheduled to have surgery for it and 14 percent stating they had taken or were receiving medication for it. The second most common intervention reported by men was AIH. Twenty percent of the men stated that they had used or were currently using this intervention.

* This is a summary of Halman et al. (1992).

Results

Exhibit 3A.1 shows respondents' attitudes about the various infertility interventions. It indicates that S/S, S/W, AID, and AIH&D were viewed the most unfavourably by both fertile and infertile couples. It is noteworthy that most of these interventions allow only one member of the couple to be a biological parent of the child. Although a couple using S/W would be biological parents, the fetus would be carried by another woman. The remaining seven interventions are generally viewed favourably by both sets of couples. Two of the reasons for the lower acceptability of IVF among the acceptable interventions may be the newness of this intervention and the high cost that is generally not covered by third-party payers in the United States. Infertile couples were more favourable than the fertile couples toward all interventions, except for adoption. Using the student *t*-test, there is a significant ($p \leq 0.01$) difference between the infertile couples' mean scores and the fertile couples' mean scores, except for IVF, AIH&D, S/W, and S/S. Adoption is the most acceptable alternative for fertile couples, while it is the seventh most acceptable alternative for infertile couples.

As can be seen in Exhibit 3A.1, infertile wives and husbands showed the same hierarchical ranking of acceptability of infertility interventions, although the wives were generally more favourable toward the use of the interventions. Fertile husbands and wives did not show the same hierarchy. For example, fertile husbands ranked IVF third while fertile wives ranked it fifth. Fertile husbands and wives generally showed agreement within couples for acceptability of infertility interventions, except for male hormones, AID, S/W, and S/S. The fertile men were significantly more accepting of the last three interventions than were fertile women.

Exhibit 3A.2 shows the structure of infertile couples' attitudes about the 11 infertility interventions. These results were generated by applying multidimensional scaling to a matrix of correlation coefficients that reflect similarities of endorsements. In the figure, small distances between interventions imply high similarity in patterns of endorsement, and large distances imply low similarity, or independence, in patterns of endorsement. As can be seen in Exhibit 3A.2, infertile couples show five clusters according to similarity of endorsement: (1) interventions in which only one member of the couple is a known biological parent or another person is involved (S/S, S/W, AID, and AIH&D), (2) IVF and AIH, (3) temporary tying of the cervix to prevent miscarriage, (4) hormone medications, and (5) adoption.

Exhibit 3A.3 shows multidimensional scaling results for fertile couples. Fertile couples show less discrimination among the 11 techniques than the infertile couples did, with three clusters being depicted: (1) interventions in which only one member of the couple is a known biological parent or another person is involved (S/S, S/W, AID, and AIH&D), (2) adoption, and (3) the remaining six interventions. All interventions for both the infertile and fertile couples are about equidistant from adoption. By comparing the

results shown in Exhibits 3A.2 and 3A.3 with those in Exhibit 3A.1, we can see that 10 interventions approximate a continuum across the diagram, moving from those interventions viewed more negatively to those viewed more favourably.

Controlling for gender, there was no significant difference in attitudes toward the use of infertility interventions. Fertility status remained the variable that showed the most differentiation, with infertile couples showing more discrimination among the interventions than the fertile couples.

Comparing the frequency of the procedures and interventions used among the infertile couples with the acceptability of various infertility interventions, one can see that, in the aggregate, couples are using interventions that are generally most acceptable to them. Adoption is the one intervention that is inconsistent with this. Although adoption was frequently pursued by infertile couples, it was the least acceptable of the interventions that infertile couples felt they could use. This result may have been influenced by the respondents who participated in this study. Couples who strongly prefer to be biological parents of their child may be the couples who seek treatment from an infertility specialist (our primary source of referral for infertile couples). Although the couples in this study may have proceeded with investigation of adoption to assure themselves of success in eventually having a child, they may not yet have been ready to accept this as their ultimate intervention.

When infertile couples are compared to fertile couples, it is evident that the infertile couples viewed all interventions more favourably than the fertile ones did, except for adoption. The explanation for this may be the same as stated previously. A different explanation is also possible. Some couples in our pretest who adopted after receiving infertility treatment spoke about not seriously considering adoption as an intervention initially because they had not considered it an alternative treatment. It is known that surprise and shock are among the first emotions felt by couples when they suspect they may be infertile. It may be that knowledge of infertility comes as such a surprise to some people that they do not recognize all the options available to them and instead focus just on seeing an infertility specialist.

Both fertile and infertile couples viewed those interventions in which only one member of the couple is a biological parent the most negatively. This may be explained by members of the couple preferring equity in relation to the child — that is, if both are unable to have a child biologically, then perhaps it is better that neither be a biological parent and that they adopt a child instead.

Exhibit 3A.1 Favourability Toward Infertility Interventions Among Married Couples in Southeastern Michigan in 1988

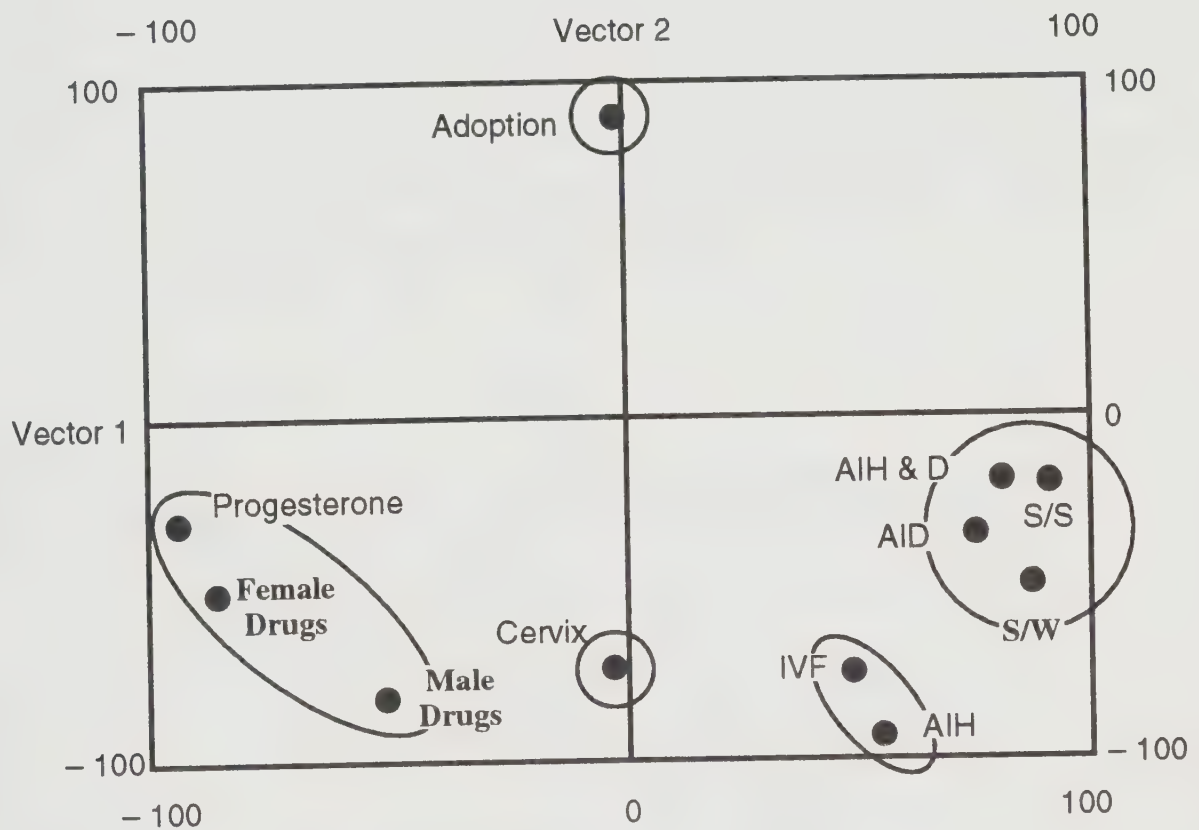
	Infertile couples			Fertile couples			Sign. of diff. between infertile couple mean and fertile couple mean
	Mean scores†		Paired t-test	Mean scores†		Paired t-test	
	Wives	Husbands		Wives	Husbands		
Male hormones	4.7	4.3	***	4.1	3.8	*	***
Artificial insemin. — husband sperm (AIH)	4.6	4.3	***	4.1	4.1	n.s.	***
Progesterone suppositories ^a	4.5	4.3	n.s.	4.0	3.8	n.s.	***
Drugs to stimulate ovulation	4.6	4.1	***	3.9	3.7	n.s.	***
Tying cervix ^a	4.4	4.0	***	3.9	3.7	n.s.	***
In vitro fertilization (IVF)	4.2	4.0	**	3.8	4.0	n.s.	n.s.
Adoption	4.1	4.0	*	4.2	4.4	n.s.	***
A.I. — husband + donor sperm (AIH + D)	2.6	2.4	n.s.	2.2	2.4	n.s.	*
Artificial insemin. — donor sperm (AID)	2.5	2.3	*	2.0	2.3	*	***
Surrogacy with wife's ova (S/W)	2.2	2.0	n.s.	1.9	2.3	***	n.s.
Surrogacy with surrogate's ovum (S/S)	1.9	2.0	n.s.	1.7	2.0	***	n.s.

† Scale ran from 5 (favourable) to 1 (unfavourable); n.s. = not significant.
a. 15% or more of the total respondents stated they did not know enough about these interventions to state an opinion.
* = $p \leq 0.1$
** = $p \leq 0.05$
*** = $p \leq 0.01$

Note: “Infertile” couples are those who have seen an infertility specialist.

Source: L.J. Halman, A. Abbey, and F.M. Andrews. “Attitudes About Infertility Interventions Among Fertile and Infertile Couples.” *American Journal of Public Health* 82 (1992), 192. Reproduced with permission of the publisher, the American Public Health Association.

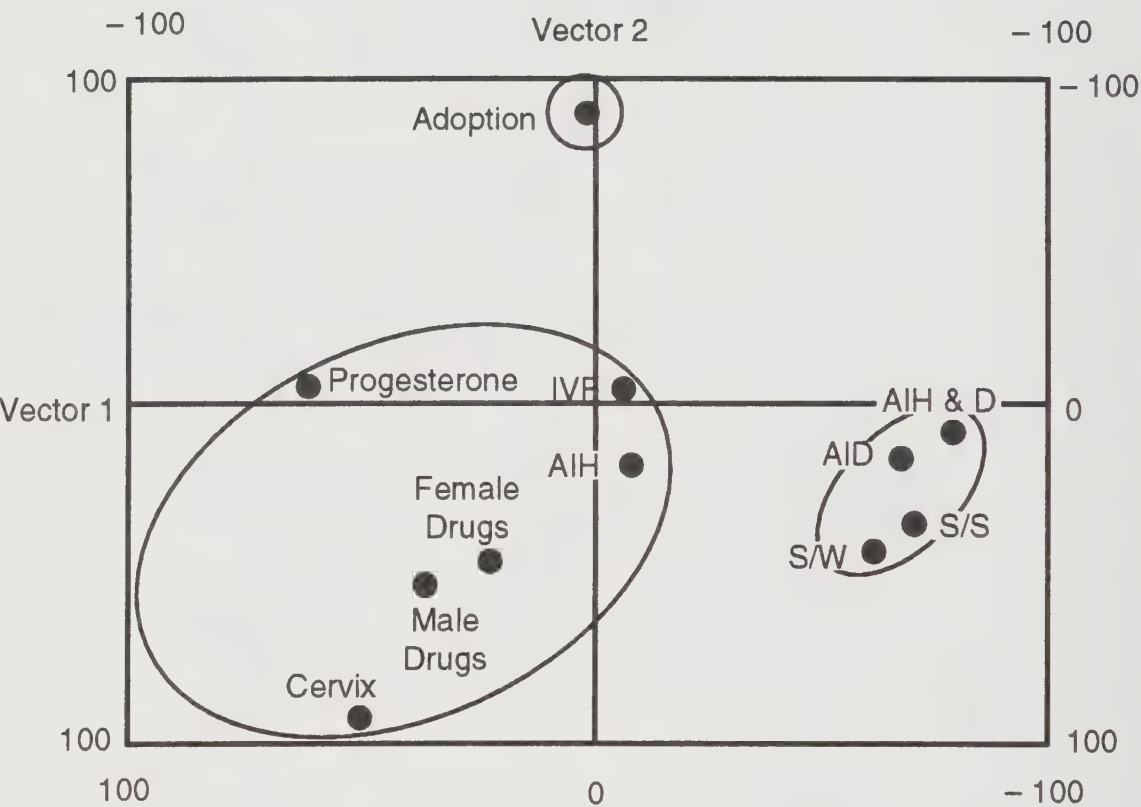
Exhibit 3A.2 Interventions for Infertile Couples Multidimensional Scaling



Kruskal's Stress = 0.10069

Source: L.J. Halman, A. Abbey, and F.M. Andrews. "Attitudes About Infertility Interventions Among Fertile and Infertile Couples," *American Journal of Public Health* 82 (1992): 194. Reproduced with permission of the publisher, the American Public Health Association.

Exhibit 3A.3 Interventions for Fertile Couples, Multidimensional Scaling



Kruskal's Stress = 0.0685

Source: L.J. Halman, A. Abbey, and F.M. Andrews. "Attitudes About Infertility Interventions Among Fertile and Infertile Couples," *American Journal of Public Health* 82 (1992): 194. Reproduced with permission of the publisher, the American Public Health Association.

The multidimensional scaling shows that, within their clusters, infertility interventions seem to follow a continuum from those that allow only one member of the couple to be a known biological parent to those that allow both spouses to be biological parents. These 10 interventions are roughly equidistant from adoption, presumably because neither member of the couple would be a biological parent with that intervention. Although we are interpreting these differences as being due to biological equity, this is only our interpretation and was not specifically asked of respondents in this study. Some people have raised questions that perhaps this could be a result of uncertainty of parenthood or invasiveness of the technique used. If it was uncertainty about biological parents, we would have expected to see adoption clustered with AID, AIH & D, S/W, and S/S. If it was due to invasiveness or high technology, we would have expected to see IVF clustered with AID and the two forms of surrogacy.

Summary

Future research is necessary to determine the extent to which the pattern of attitudes found here is representative of the general population. These findings throw light on the attitudes that couples experiencing fertility problems may have toward some interventions that could allow them to conceive. These findings could serve as a general guide for likely acceptance of certain interventions. They may also indicate the degree of emotional support some couples may require to make an informed decision about the use of a particular technique. Couples may benefit by having the alternative of adoption addressed and given legitimacy as an acceptable intervention from the onset of infertility treatment. The finding that infertile couples were more favourable toward various interventions than fertile couples suggests that people's attitudes about infertility interventions become more positive when they are confronted with personal necessity and are in receipt of more information.

The Importance of Social Relationships*

Introduction

Numerous studies document that social support from friends and family can reduce the negative impact of stress on physical and psychological well-being (House et al. 1988; Kessler et al. 1985). Conversely, the receipt of interpersonal conflict from significant others during times of crisis can lead to increased stress and reduced well-being (Abbey et al. 1985; Abbey and Andrews 1985; Shinn et al. 1984).

Many infertility researchers have described how insensitive responses from significant others can increase the amount of stress that members of infertile couples experience. Friends and family members frequently make comments and offer advice that infertile couples find distressing. Network

* This is a summary of Abbey et al. (1991b).

members may ask each month if the woman is pregnant yet, and suggest folk cures, alternative coital positions, or that the couple "just relax" (Andrews 1984). Lalos and colleagues (1985) found that more than 80 percent of the small sample of infertile couples they interviewed felt they had received no genuine emotional support from friends or family members.

Members of infertile couples frequently rely on each other for social support. While this can sometimes make the couple's relationship stronger, it can also place a burden on it. Because each member of the couple is in crisis, it may be difficult to provide adequate emotional support for each other. As Mahlstedt (1985, 337) observed, "because both the man and the woman are hurting, tired, and under great pressure, ... they may become less able to fulfill each other's needs."

There were two main purposes for the analyses described in this section. The first was to obtain descriptive information about the social support that members of infertile couples received. The second was to examine the relationship between social support, interpersonal conflict, and well-being.

Results

Exhibit 3B.1 presents descriptive information about people with whom infertile couples talked about their problem and about how such discussions made them feel. At the time of the initial interview, 96 percent of the infertile women and 88 percent of the infertile men had talked with friends and/or family about their fertility problem during the previous 12 months. While this is a high percentage for both genders, women talked significantly more often with others than men did. When asked how such discussions made them feel, both women and men reported feeling somewhat better after talking with friends and family. Men and women, however, gave somewhat different explanations for these responses. Women were significantly more likely than men to state that there were both positive and negative effects of talking with friends and family (e.g., gave them a shoulder to cry on, said something that made them feel guilty). In contrast, men were significantly more likely than women to say that they were not usually influenced by what others had to say to them. Thus, women were moderately satisfied with the reactions of others because others said both helpful and unhelpful things, while men were moderately satisfied because they really did not care very much about what others had to say.

Exhibit 3B.1 The Importance of Social Relationships

	Women	Men		Women	Men
<i>Wave 1:</i>					
Percentage who talked about fertility problem with family and friends in last 12 months	96	88**	For those who talked, how did it make them feel?	3.7	3.7 ^a
Percentage who talked with others who had a fertility problem in last 12 months	73	53**	For those who talked, how did it make them feel?	4.1	3.9 ^a
<i>Wave 3:</i>					
Percentage who talked about fertility problem with family and friends in last 12 months	91	76**	For those who talked, how did it make them feel?	3.7	3.5 ^{***a}
Percentage who talked with others who had a fertility problem in last 12 months	74	62**	For those who talked, how did it make them feel?	4.0	3.6 ^{***a}
Percentage who ever participated in a group of people with fertility problems	13	11	For those who talked, how did it make them feel?	4.0	3.8 ^a
			For those who did not talk, do they want to talk?	1.7	1.4 ^{**b}

* $p < 0.09$ ** $p < 0.05$

^a response options
 1 = much worse
 3 = neither better nor worse
 5 = much better

^b response options
 1 = not at all
 4 = a great deal

Fewer study participants had spoken about their fertility problem with someone else who was infertile. Seventy-three percent of the women and 53 percent of the men had had such discussions at the time of the initial interview (a significant gender difference). These discussions with other infertile individuals made women feel slightly better than they made men feel. Women's answers focussed on positive responses they had to such conversations (e.g., realized they weren't the only ones who felt that way), while men's answers focussed on their lack of concern with others' comments.

These same questions were repeated at the two-year follow-up interview. At Wave 3, the vast majority of study participants had talked with friends and family about their fertility problem in the previous 12 months. However, the percentage of respondents who had talked with network members was somewhat lower than it was at Wave 1, perhaps because the situation was less new and they felt there was less to talk about with others. The percentages of women who had talked with infertile others were nearly identical at Waves 1 and 3, although more men had spoken with other infertile individuals at Wave 3 than at Wave 1. Women were slightly more satisfied than men with their conversations with friends and family and with other infertile individuals.

At Wave 3 only, women and men were asked if they had participated in a group of infertile individuals. Self-help groups are popular for a variety of types of problems, and individuals often report finding such groups to be socially supportive. Less than 15 percent of the men and women in this study had participated in any type of self-help group. Those who did participate in these groups rated them as being quite helpful (again, women's ratings were slightly more positive than were men's). Most of the individuals who had not participated in a self-help group indicated they were not interested in joining one (women were slightly more interested in participating in a self-help group than men were). This suggests that individuals self-select into these groups: those who are interested seek them out and find them to be helpful, while those who are disinterested choose not to attend groups.

Exhibit 3B.2 summarizes the results of a series of multiple regressions in which the effects of the following variables on the quality of marital life and sexual dissatisfaction of members of infertile couples were examined: social support from network members (social support satisfaction), social support from one's spouse (esteem and affirmation), interpersonal conflict from one's spouse (negative affect and disapproval), stress, and self-esteem. Preliminary analyses (not shown in the exhibit) demonstrated that these variables exerted main effects rather than interactive effects on well-being.

Exhibit 3B.2 The Importance of Social Relationships

Predictors	Marital life quality		Sexual dissatisfaction	
	Women	Men	Women	Men
Fertility-problem stress	-0.19**	-0.26**	0.31***	0.17**
Self-esteem	n.s.	n.s.	-0.33***	-0.39***
Social support satisfaction	0.38***	0.39**	n.s.	n.s.
R ²	0.20	0.28	0.35	0.24
Fertility-problem stress	-0.21**	-0.16**	0.32***	0.11
Self-esteem	n.s.	n.s.	-0.34***	-0.33***
Esteem support	0.49***	0.54***	-0.12*	-0.27***
R ²	0.30	0.40	0.36	0.30
Fertility-problem stress	-0.20**	-0.17**	0.31***	0.14*
Self-esteem	n.s.	n.s.	-0.34***	-0.36***
Affirmation support	0.34***	0.48***	-0.15**	-0.13*
R ²	0.20	0.34	0.36	0.26
Fertility-problem stress	-0.13*	-0.18**	0.30***	0.15*
Self-esteem	n.s.	n.s.	-0.35***	-0.38***
Negative affect conflict	-0.54***	-0.48***	0.15**	0.11
R ²	0.35	0.35	0.36	0.25
Fertility-problem stress	-0.18**	-0.22**	0.30***	0.16**
Self-esteem	n.s.	n.s.	-0.33***	-0.38***
Disapproval conflict	-0.44***	-0.37***	0.16**	0.03
R ²	0.26	0.26	0.37	0.24

* p < 0.09

** p < 0.05

*** p < 0.01

n.s. = not significant

Source: A. Abbey, F.M. Andrews, and L.J. Halman. "The Importance of Social Relationships for Infertile Couples' Well-Being." In *Infertility: Perspectives from Stress and Coping Research*, ed. A.L. Stanton and C.A. Dunkel-Schetter. New York: Plenum Press, 1991, 79. Reproduced with permission of the publisher, Plenum Press.

For marital life quality, the predictors were similar for women and men. As hypothesized, network and spouse social support were positively related to marital life quality, while spouse interpersonal conflict was negatively related to marital life quality.

Not surprisingly, network social support was not a significant predictor of sexual dissatisfaction; this may be too personal an issue for network

members to affect. As predicted, spouse support was significantly negatively related to sexual dissatisfaction for both women and men. Spouse interpersonal conflict was positively related to sexual dissatisfaction only for women.

Summary

Social support from one's spouse, friends, family, and similar others enhanced members of infertile couples' well-being. In contrast, receiving negative affect and disapproval from one's spouse reduced well-being for members of infertile couples. These findings were true for both women and men, although in several instances women showed stronger effects than did men.

Expected and Desired Number of Children

Introduction

We examined the relationships of fertility status, gender, income, age, education, and length of time spent in trying to have a child with the desired and expected number of children among fertile and infertile couples. The following variables were explored for intervening effects: problem-solving coping, escape coping, self-esteem, self-efficacy, conflict between the spouses, stress of the problem (for infertile couples the fertility problem and for fertile couples their self-identified biggest problem), social support from one's spouse, the availability of social support from network members, confidence in having a biological child, importance of children, and pride in work.

Data and Variables

Independent variables

To measure fertility status, individuals were asked if they were trying to have a baby — if so, how long they had been trying, and whether or not they believed they were having a difficult time. Although we first considered using the common medical definition of infertility (trying to have a child for 12 months or longer with unprotected intercourse without a viable pregnancy), several couples had sought treatment from infertility specialists before they had tried to have a child for 12 months. Thus, it was decided to include couples who had already been involved in discussions and decision making with their physicians about infertility and its treatment with the other infertile couples. This procedure enabled us to get a more accurate picture of desired and expected numbers of children for couples who are confronted with infertility treatment.

Income, age, education, and length of time trying to have a child were measured by single questions for each concept.

Dependent variables

Although it is recognized that the Coombs' IN scale for number preference of children is generally used to measure an individual's preference for children today, it was decided not to use this scale because of the potential sensitivity of repeatedly asking infertile couples about the number of children they wanted to have if they were unable to have their original desired number. The ideal or desired number of children in the study was measured by asking all individuals one question: "Ideally, if life could be just the way you want it to be, how many children would you have?" (Freedman and Goldberg 1977). Interviewers were instructed to inform the respondents that this number included adopted children, if the respondents raised the question. Answers ranged from 0 to 6.

The expected number of children in this study was derived from the mean of answers to three questions that were asked of all individuals:

- (1) "sometimes the number of children people want differs from the number they have. How many children do you expect to have by the time your family is completed?" Answers ranged from 0 to 5;
- (2) "what do you think is the largest number of children you will probably have, including adopted children?"; and
- (3) "what do you think is the smallest number of children you will probably have, including adopted children?" These questions were derived from previous work by Freedman and Goldberg (1977).

Intervening variables

Multi-item scales were used to measure the intervening variables, which included problem-solving coping, escape coping, self-esteem, self-efficacy, conflict between the spouses, stress, social support from spouse, availability of social support from network members, confidence in having a biological child, importance of children, and work identification. Factor and cluster analyses were performed using the present data to confirm or determine which items would enter each scale. The stress scale was based on answers to nine items; other scales were based on two to six items each. All items used to form scales were answered using sets of four or five ordered categories, and scales were constructed by averaging the responses to these categories. Homogeneity reliability coefficients (Cronbach alphas) were computed for all scales and ranged from 0.60 to 0.88.

Results

To examine differences between desired and expected number of children, couples' preferences were examined for gender and fertility differences.

Exhibit 3C.1 shows the mean desired and expected number of children by gender. Both fertile and infertile couples desired more children than they expected to have. There was a significant difference in expected number of children ($p < 0.001$; not shown in this table) due to fertility

status, with fertile couples expecting more children than infertile couples. The only significant difference shown for gender was between infertile women and infertile men. Infertile women had a larger desired number of children than infertile men ($p < 0.01$), with infertile women desiring 2.78 children and infertile men desiring 2.55. For both genders, the mean desired number was greater than the mean expected number ($p < 0.001$).

Exhibit 3C.1 Mean Ideal and Expected Number of Children by Gender for People in Southeastern Michigan, 1988

	Fertile			Infertile		
	Women (n = 90)	Men (n = 90)	Paired t-test	Women (n = 184)	Men (n = 184)	Paired t-test
Mean ideal number	2.47	2.61	n.s.	2.78	2.55	*
Mean expected number	2.06	2.11	n.s.	1.75	1.74	n.s.
Paired t-test	**	**		**	**	

* $p \leq 0.01$
** $p \leq 0.001$
n.s. = not significant

To examine the association of predictor and intervening variables with the outcome variables more closely, a path analysis was conducted using multiple regression and controlling for fertility status. The least promising variables — i.e., those having Pearson r correlations less than 0.20 — were dropped. The predictor variables remaining included year born and income; intervening variables included problem solving as a means of coping, the importance of children, and confidence in having a biological child; and outcome variables were the desired number of children and the expected number of children. Exhibit 3C.2 depicts this path analysis.

Examining the residuals for the outcome variables, one finds the residuals for the expected number of children were smaller than for the desired number of children, showing that 35 percent of the variance is explained for fertile individuals and 21 percent of the variance is explained for infertile individuals. More variance is explained for the expected number of children than for the desired number of children.

The predictor variable with the strongest effect was year born, depicted by the bold line. The younger the individuals were, the more importance

children held for them, the more children they desired, and the more children they expected to have. The more importance children held for individuals, the more children they desired, and the more children they expected to have. All path coefficients were significant at the $p < 0.01$ level for these effects.

Examining the path coefficients for differences between fertile and infertile individuals, the only relationship with a significant difference was between age and confidence in having a biological child. Among infertile individuals, the younger the person, the higher the confidence in having a biological child. Among fertile couples, age was not important in relation to fertility confidence. This seems reasonable, since younger infertile couples may be more conscious of their desire to have a child and thus could have a higher confidence in having a biological child. Fertile couples may assume they will be fertile and do not think about their fertility as much. This was the only predictor or intervening variable to show a difference due to fertility status.

Summary

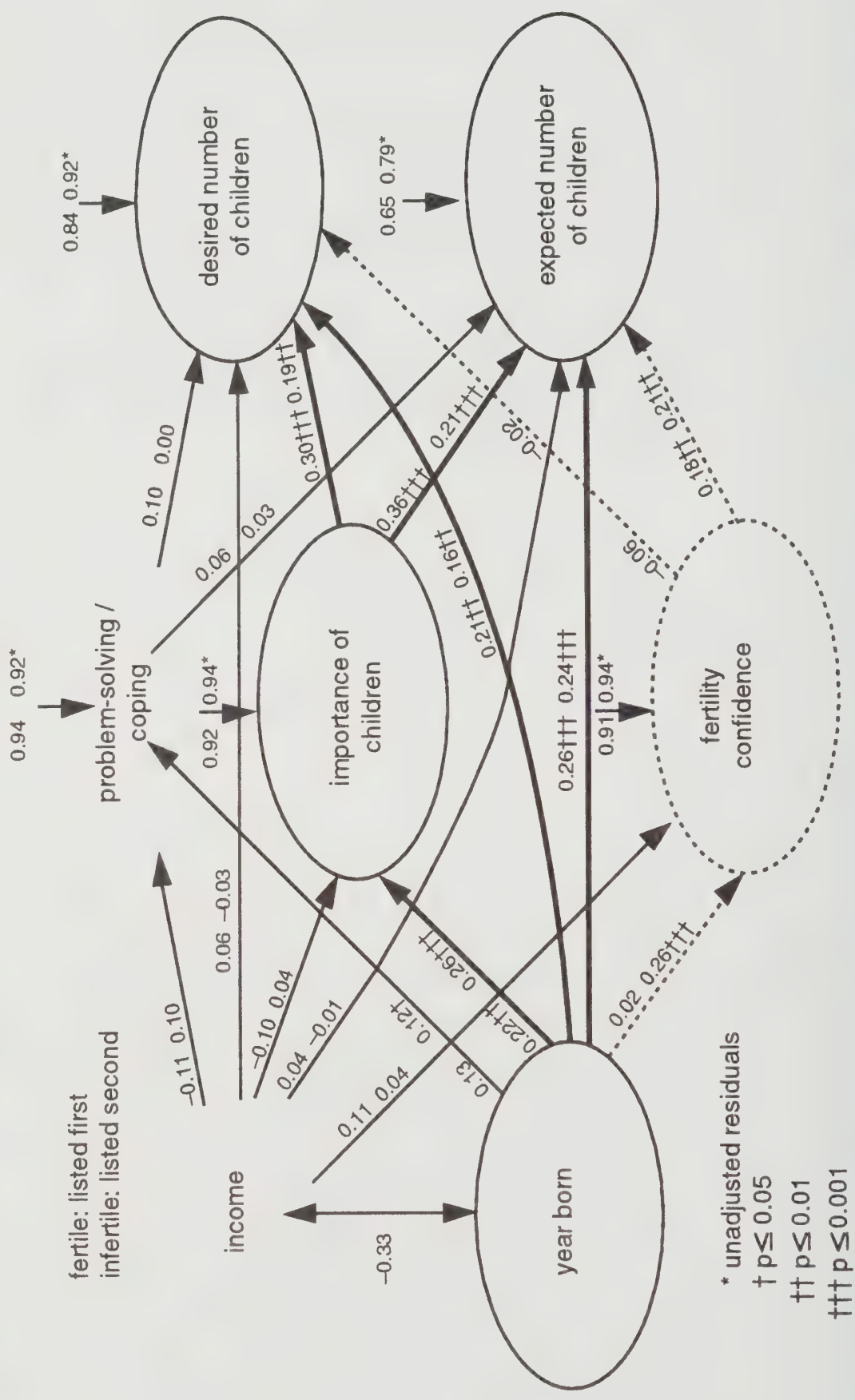
In summary, both fertile and infertile couples desired more children than they expected to have. Infertile individuals were not very different from fertile individuals with respect to the number of children they desired, but, when confronted with the possibility of not having children or having a limited number of children, they realistically lowered their expectations.

Education did not show any appreciable relationships with expected or desired number of children. Although Coombs and Fernandez (1978) found that individuals with a college education preferred fewer children than did individuals with a high school education or less and that women with lower incomes desired fewer children than did women with higher incomes, the respondents in this study were rather homogeneous as to education and income; it is therefore not surprising that relationships were not found.

Income showed major correlations for fertile men, fertile women, and infertile men, although it did not show a major correlation for infertile women. Perhaps the absence of the expense of infertility interventions allowed fertile individuals to expect more children. Infertile men experienced greater fertility-problem stress if they had a lower income. Perhaps infertile men felt more responsible for the financial aspects of infertility treatment than infertile women did.

Many of the psychosocial variables that were expected to have intervening effects on the number of children desired or realistically expected did not have the influence initially expected. Escape coping, self-esteem, self-efficacy, social support, the stress of the problem, the conflict between the spouses, and pride in work did not have an appreciable relationship with the number of children desired or expected. It is

Exhibit 3C.2 Path Analysis Controlling for Fertility Status



possible that the timing of the data collection in this study may have influenced some of these findings. Perhaps some variables such as social support, coping, self-esteem, and self-efficacy influence a person more when initially considering whether or not to seek infertility treatment than after infertility treatment has begun. Hence, in the analysis, the importance of children to the individual had the greatest relationship. In the path analysis, age and importance of children had the major influences on these numbers. Thus, the younger the individuals — i.e., the more years left on the biological clock for a woman to bear a child, and the more importance children had for individuals — the more children they desired and expected to have. In the demographic data presented earlier, there was a difference in mean age for infertile women and fertile women of four years. However, even after controlling for fertility status, the same relationships were seen with importance of children.

What does this tell about people's motivation for the number of children they want? Perhaps younger people who envision many future years of childbearing foresee more family life, which would include children for themselves. People who are older with fewer childbearing years remaining may have found other avenues that are just as fulfilling and are willing to accept the prospect of fewer children.

One difference was seen when gender was examined. Although fertile men and fertile women desired and expected about the same number of children, infertile women desired more children than did infertile men. What was occurring with infertile women to cause this difference? One possible explanation for this is that since the infertile woman is the member of the couple on whom infertility treatments often focus, regardless of whether the physical problem is the man's or the woman's, the woman also becomes more focussed on the end product, a child, and the importance of children may then rise in her estimation. Also, women have been socialized from an early age to be concerned with pregnancy, childbirth, and raising children. This has been used as an explanation for why it is usually the wife who initiates the infertility investigation (Sundby 1988). In addition, it is the woman who must contend with taking her daily basal body temperature, who must plot her monthly menstrual cycle, and who worries about starting her menses or not, reminding her of the fact that she is not pregnant. Freedman et al.'s (1965) earlier findings and Udry's (1983) hypothesis that the health of the wife (in this instance infertility) could negatively impact on the expected number of children also support this finding.

The results of this research show that the decisions a couple makes about desired and expected numbers of children partly depend on their age and the importance children hold for them. Health care providers may want to explicitly discuss this topic with older infertile individuals who strongly desire a child to ensure that their expectations are realistic, or possibly refer them to an appropriate source to help them realistically appraise the number of children they might have.

The Source and Nature of the Fertility Problem and the Frequency and Timing of Sexual Intercourse

Introduction

This portion of the report describes analyses of the source and nature of the fertility problem, frequency of sexual intercourse, and timing of intercourse. The distributions and levels of these variables, relationships among them, and agreements between wives and husbands are explored. There is also information on how some of these variables relate to others, including sexual dissatisfaction, sexual self-esteem, fertility-problem/biggest-problem stress, and various measures of life quality. A summary of the results is presented at the end. All results come from data from the first interview. This is probably the best of our data sets for these analyses because at later interviews some fertility-problem couples had “solved” their problem by bearing a child, adopting a child, or giving up trying to become parents — hence the case base becomes smaller.

Results

Developing variables to reflect source of fertility problem proved to be a challenging task. There were two (linked) sources of data — one asking about the source of the problem, the other asking about the nature of the problem. Together, these produced a substantial amount of rather complex information.

Source of Fertility Problem

The simplest data came from question #R2 in the first interview questionnaire, which was asked of people who (1) said they were having a difficult time having a baby, and (2) had been trying to get pregnant for 12 months or more. This question asked: “Fertility problems can be due to physical problems that the wife has, physical problems that the husband has, or physical problems they both have. Which is true in your case?” In addition to these three categories, we also coded a “Don’t know or unexplained” category.

The distribution of answers is shown in Exhibit 3D.1.

Wives and husbands in the same couple showed substantial agreement in their answers to #R2. Of 150 couples where both the wife and husband gave a usable response, 81 percent gave the same response. All of the discrepancies involved spouses differing in their use of the “both” or “unknown” categories. Cramer’s V between the wife’s answers and the husband’s answers was 0.72.

Exhibit 3D.1 Reported Source of Fertility Problem

Respondents	Wife	Husband	Both	Unknown
Wives	47%	11%	30%	12%
Husbands	45%	9%	31%	15%

Nature of Fertility Problem

Additional useful information came from question #R3, which was asked of those answering item #R2 and who said they knew what the problem was. Question #R3 read: "To the best of your knowledge, what are the specific physical reasons, past and present, for this fertility problem?" Using a rather detailed two-digit code, we coded up to five responses from the wife and up to five responses from the husband.

A great many different combinations of causes emerged, and no one cause or combination of causes predominated, even after we grouped some of the answers into more homogeneous categories. The most frequently mentioned cause was female structural problems (involving ovarian, uterine, cervical, tubal, scarring, mucus, and/or diethylstilbestrol [DES]-related problems); 16 couples (out of 146 considered here) attributed their infertility solely to these. The next most frequently mentioned cause ($n = 13$) was female hormonal problems. Most couples mentioned combinations of causes, but few mentioned the same combination.

For subsequent analysis we determined, for every couple, whether each of eight generic causes had been mentioned by either the wife or husband. These eight causes and the number of couples who mentioned them are shown in Exhibit 3D.2. Of course, the sum of their answers is more than the number of couples on which this analysis is based — $n = 146$ — because most couples mentioned more than one type of problem.

Exhibit 3D.2 Reported Cause of Fertility Problem

Problem	n
Female hormonal	58
Female structural (ovarian, uterine, cervical, etc.)	68
Female endometriosis	43
Female behavioural (e.g., sexually transmitted diseases [STDs], age, weight, stress)	23

Exhibit 3D.2 (cont'd)

Problem	n
Female other (e.g., genetic, premenstrual syndrome [PMS], other medications)	20
Male sperm	65
Male behavioural (e.g., STDs, weight, stress)	15
Male other (e.g., genetic, other medications)	12

Match Between Reports of Source and Nature of Fertility Problem

We also considered how well the specific nature of the problems people mentioned matched the source they gave in response to #R2 (problem is due to wife/husband/both). The match was good, and about equally so for wives and husbands. Cramer's Vs between the respondents' answers to the summary question and a code developed by the research team based on respondents' list of specific causes were 0.84 and 0.82, for wives and husbands, respectively.

Frequency and Timing of Sexual Intercourse

Frequency of sexual intercourse. Data on frequency of sexual intercourse came from question #G2, which read: "What is your current frequency of sexual intercourse — would you say less than once a month, about once a month, 2 or 3 times a month, about once a week, 2 or 3 times a week, or 4 or more times a week?" This question was asked of all respondents.

Distributions for all wives and husbands, and for wives and husbands with fertility problems, are shown in Exhibit 3D.3. The respondents with fertility problems were not markedly different from those without.

Wives and husbands in the same couple showed high but not perfect agreement in their answers about frequency of sexual intercourse. Of 270 couples where both the wife and husband gave a usable response, 54 percent gave the same response. Nearly all of the discrepancies involved answers that fell in adjacent categories. In only 4 percent of couples did the wife and husband give answers that were not the same or adjacent to one another. Gamma was + 0.84 between wives' and husbands' answers.

There are, of course, several explanations for different answers. In addition to differences in actual behaviour recall between wives and husbands, there is the possibility they both reported the same behaviour accurately but gave different answers because they referred to different time frames. The phrase "current frequency" in the question is not specific regarding the intended time frame.

Exhibit 3D.3 Frequency of Sexual Intercourse as Reported by All Wives and Husbands and by Wives and Husbands with Fertility Problems (FP)

Respondents	n	< 1/mo	1/mo	2-3/mo	1/wk	2-3/wk	4+/wk
Wives (All)	273	1%	4%	12%	31%	45%	7%
Husbands (All)	272	2%	2%	20%	28%	42%	6%
Wives (FP)	175	1%	3%	14%	30%	48%	4%
Husbands (FP)	174	1%	2%	21%	30%	40%	6%

Timing of sexual intercourse. Question #G3 asked about timing of sexual intercourse. It read: "Does your frequency of sexual intercourse depend on when (you/your wife) ovulate(s) (is most likely to become pregnant)? That is, are you more likely to have intercourse then, less likely to have intercourse then, or does it make no difference?" The question was addressed to all respondents.

Distributions for wives and husbands were virtually identical. Not surprisingly, most of the wives and husbands who said their sexual intercourse was more likely to occur when the wife was ovulating were those who were trying to solve a fertility problem, though only slightly over half of those couples reported timing their intercourse to match ovulation. Distributions for all respondents, for those with fertility problems and for those who were presumed fertile, are shown in Exhibit 3D.4.

Exhibit 3D.4 Timing of Intercourse Relative to Wife's Ovulation for All Couples, Fertility-Problem (FP) Couples, and Presumed-Fertile (PF) Couples

Respondents	n	Less likely	No difference	More likely
Wives (All)	271	4%	55%	41%
Husbands (All)	270	5%	55%	40%
Wives (FP)	182	2%	42%	56%
Husbands (FP)	182	2%	40%	58%
Wives (PF)	89	9%	84%	7%
Husbands (PF)	88	11%	85%	4%

Data on this item were available from both wives and husbands in 266 couples, and 76 percent gave the same answer. Most of the mismatches involved one couple saying "no difference" and the other saying "more

likely.” Gamma for the relationship between wives’ and husbands’ responses was + 0.86.

Frequency of sexual intercourse and timing for ovulation. When all respondents (both those with and those without a fertility problem) were analyzed together, there was a mild tendency for those who reported the highest frequencies of sexual intercourse to say that its timing did not depend on when the wife ovulated or was less likely when the wife ovulated. This pattern was a bit stronger for husbands (gamma = -0.19, $p = 0.03$) than for wives (gamma = -0.14, $p = 0.12$).

Because this pattern might differ according to whether the couple was experiencing a fertility problem, we looked at just the subgroup of couples who had a fertility problem. Here the relationship was stronger and statistically significant for both members of the couple. (Among husbands, gamma = -0.29, $p = 0.01$; among wives, gamma = -0.23, $p = 0.05$.) For wives and husbands in couples who did not have a fertility problem, there was virtually no relationship.

Frequency of Intercourse and Source/Nature of Fertility Problem

An extensive series of analyses showed there to be no strong relationships among couples with fertility problems between frequency of sexual intercourse and either the source or nature of the fertility problem. There were, however, a few mild relationships linked to the nature of the problem.

Source of problem. Among fertility-problem couples, there were no significant relationships between frequency of sexual intercourse and whether the fertility problem was due to the wife, the husband, both, or unknown factors. In six analyses that looked at this relationship using different sets of respondents and different sources for the information about who had the problem (#R2 or #R3), Cramer’s Vs were all in the range 0.15 to 0.19.

Specific nature of problem. When we looked at the specific nature of the fertility problem and related it to frequency of sexual intercourse, we again found mostly weak and insignificant relationships. There was a slight (insignificant) trend for husbands to report less frequent intercourse if they said their wives had a problem involving endometriosis (gamma = -0.19, $p = 0.15$), and the same trend appeared in the data for wives (gamma = -0.23, $p = 0.07$). Also, frequency of sexual intercourse tended to be a little lower if there was a problem with male sperm (gammas = -0.30, $p = 0.02$, and -0.14, $p = 0.26$, for wives and husbands, respectively).

Relationships Between Frequency of Intercourse and Psychosocial Variables

Frequency of sexual intercourse and sexual self-esteem. As one might expect, we found modest positive relationships between frequency of sexual intercourse and scores on our sexual self-esteem index. Individuals who reported more frequent sexual intercourse tended to report higher levels of sexual self-esteem than others. This was true for both wives (gamma = +0.17, $p = 0.06$, $n = 273$) and husbands (gamma = +0.24, $p = 0.01$, $n = 272$).

Frequency of sexual intercourse and sexual dissatisfaction. Frequency of sexual intercourse was substantially related in the expected direction to our index of sexual dissatisfaction. More frequent intercourse accompanied lower levels of dissatisfaction. Gammas were -0.29 , $p < 0.001$, and -0.44 , $p < 0.001$, for wives ($n = 272$) and husbands ($n = 272$), respectively.

Frequency of sexual intercourse and age, stress, and life quality. From analyses conducted prior to those reported here, we know that frequency of sexual intercourse relates negatively to age ($r = -0.2$). Intercourse frequency also relates negatively to fertility-problem or biggest-problem stress for husbands ($r = -0.2$ to -0.3), but less so for wives ($r = 0.0$ to -0.3). Intercourse frequency relates positively to several aspects of life quality, but more strongly for husbands ($r = 0.2$ to 0.6) than for wives ($r = 0.0$ to 0.5). The highest links to life quality are with our scale of satisfaction with intimacy/romance/sex.

Relationships Between Timing of Intercourse and Other Variables

Timing of intercourse and source/nature of fertility problem. Among couples with fertility problems, there were hints (weak but statistically significant for husbands, not significant for wives) that timing sexual intercourse to coincide with when the wife was ovulating was more common for couples where the source of the problem was the wife or unknown than where the problem was the husband (or both husband and wife). Cramer's Vs were 0.20 for husbands ($n = 173$) and 0.15 for wives ($n = 173$).

Specific nature of problem. In general, timing of sexual intercourse to coincide with when the wife ovulated was not linked to the specific nature of couples' fertility problems. The exception, which emerged in responses from both husbands and wives, was when the problem involved the husband's sperm or some non-behavioural other male factor. In these cases, both wives and husbands were less likely to say intercourse was timed to coincide with the wife's ovulation, and more likely to say the timing of intercourse did not matter, than when there was another type of problem. These relationships were a bit stronger in data from husbands (where Vs were about 0.20 , $n = 173$) than in data from wives (where Vs were about 0.15 , $n = 173$).

Timing of sexual intercourse and sexual self-esteem. For both wives and husbands, relationships between sexual self-esteem and whether intercourse was timed to match the wife's ovulation were weak and not statistically significant.

Timing of sexual intercourse and sexual dissatisfaction. When all respondents were considered together, there was some tendency for dissatisfaction to be higher when sexual intercourse was timed to coincide with ovulation. This tendency was a little stronger for wives (gamma = 0.22 , $p = 0.02$) than for husbands (gamma = 0.13 , $p = 0.17$).

To see whether this applied only to the fertility-problem couples, we ran the analysis separately for them and for the presumed-fertile couples. The relationship was stronger in the fertility-problem couples (for wives, gamma = 0.28 , $p = 0.01$; for husbands, gamma = 0.23 , $p = 0.07$), and it

virtually disappeared for wives and husbands in presumed-fertile couples, most of whom did not time intercourse either to match or to miss the wife's ovulation.

Relationships Between Source of Fertility Problem and Sexual Self-Esteem and Sexual Dissatisfaction

There were no statistically significant relationships between source of fertility problem (wife/husband/both/unknown) and either sexual self-esteem or sexual dissatisfaction in data from wives or husbands.

Relationships Between Nature of Fertility Problem and Sexual Self-Esteem and Sexual Dissatisfaction

Sexual self-esteem. None of the relationships between the presence/absence of a specific type of fertility problem and sexual self-esteem was statistically significant, and all were weak. There was a tendency, more pronounced in data from husbands than from wives, for these relationships to be negative — i.e., sexual self-esteem tended to be lower when a specific problem was known, particularly if it was a male problem. The strongest relationship was a $\gamma = -0.36$ ($p = 0.12$) between sexual self-esteem and the presence of a male behavioural problem (e.g., STD, weight, stress, general physical condition, etc.).

Sexual dissatisfaction. Of 18 relationships examined between the presence/absence of a specific type of fertility problem and sexual dissatisfaction, none was statistically significant. A moderate relationship occurred in data from husbands and indicated that those who had a sperm problem tended to score higher on sexual dissatisfaction than those who did not have this problem ($\gamma = +0.24$, $p = 0.06$). A similar but not statistically significant pattern occurred for husbands who had a behavioural problem: they expressed more sexual dissatisfaction than did husbands without a behavioural problem ($\gamma = +0.31$, $p = 0.16$). Some weak positive (but not statistically significant) relationships were also visible in data from wives. They scored higher on sexual dissatisfaction if they had a behavioural problem ($\gamma = +0.17$, $p = 0.33$) or an "other" problem ($\gamma = 0.28$, $p = 0.10$).

Summary

In general, there was good agreement between wives and husbands in their reports on source of fertility problem, frequency of sexual intercourse, and whether intercourse is timed to match the wife's ovulation. Reports about the source of fertility problem also agreed well with later information about the nature of the problem.

Also, as might be expected, higher levels of sexual self-esteem and lower levels of sexual dissatisfaction tended to accompany more frequent sexual intercourse and not trying to time intercourse to match ovulation. In prior analyses we have found frequency of sexual intercourse to be positively related to several evaluations of life quality and negatively related to age and levels of stress.

Distributions are presented for source and nature of fertility problem and for frequency and timing of sexual intercourse. There was substantial variation in each of these. Couples with fertility problems did not differ

from those without fertility problems on frequency of sexual intercourse, but (as might be expected) were much more likely to time their intercourse to match the wife's ovulation.

There are only a few relationships between either frequency or timing of intercourse and the source or nature of a fertility problem. Most of these few relationships involve male-based fertility problems and are in expected directions (e.g., lower coital frequencies for couples where the husband had a sperm problem). Although not foreseen, we also found that when the fertility problem was linked to a male factor, couples were less likely to time their intercourse to match ovulation than when there was another type of fertility problem. With the exceptions noted, neither the source nor nature of a fertility problem had much to do with most couples' current sexual behaviour.

Similarly, there are only a few relationships between either sexual self-esteem or sexual dissatisfaction and the source or nature of the fertility problem. These few also are in expected directions. For both wives and husbands, sexual dissatisfaction tended to be modestly higher when the individual knew that a particular fertility problem pertained to her/himself.

Part 4. Selected Factors Linked to Infertile Couples' Subjective Well-Being

Psychosocial Factors and Infertility: How Different Are Fertility-Problem Couples from Other Couples?*

Introduction

This part of the paper presents analyses designed to explore differences in well-being between fertility-problem couples and presumed-fertile couples. The general strategy involved the use of causal modelling to specify a "psychosocial system" consisting of a set of hypothesized causal linkages among a set of relevant concepts, and then considering whether the hypothesized system comes sufficiently close to predicting what is actually observed in the real world to lead one to think the hypothesized system is plausible. Furthermore, thanks to some special features of the computer software (Bentler 1989), it is possible to test whether each linkage in the system operates the same way for the fertility-problem couples and the presumed-fertile couples.

The causal model is shown in Exhibit 4A.1. Because the marital domain is especially important for couples facing a fertility problem, and because we have data from both wives and husbands, the model focusses on the roles of stress and of marriage factors in accounting for subjective well-being (life quality). In accord with prevailing theory, the model says that stress may have direct effects on the four marriage factors — marital conflict, sexual self-esteem, sexual dissatisfaction, and frequency of

* This is a summary of Andrews et al. (1992).

intercourse — and also a direct effect on subjective well-being — for example, on evaluations of one's own marriage. In addition, the four marriage variables themselves may have direct effects on well-being. Of course, this means that stress can also have indirect effects (through the marriage variables) on subjective well-being. This set of causal dynamics is hypothesized to apply to wives, shown in the upper part of the model, and to husbands, shown in the lower part.

The model allows for some linkages between the members of a couple. How much stress one member experiences is linked (by an amount that is to be determined) to how much stress the other member experiences. Also, the model explicitly allows for each member's feelings about life quality to have a direct effect on the other member's feelings.

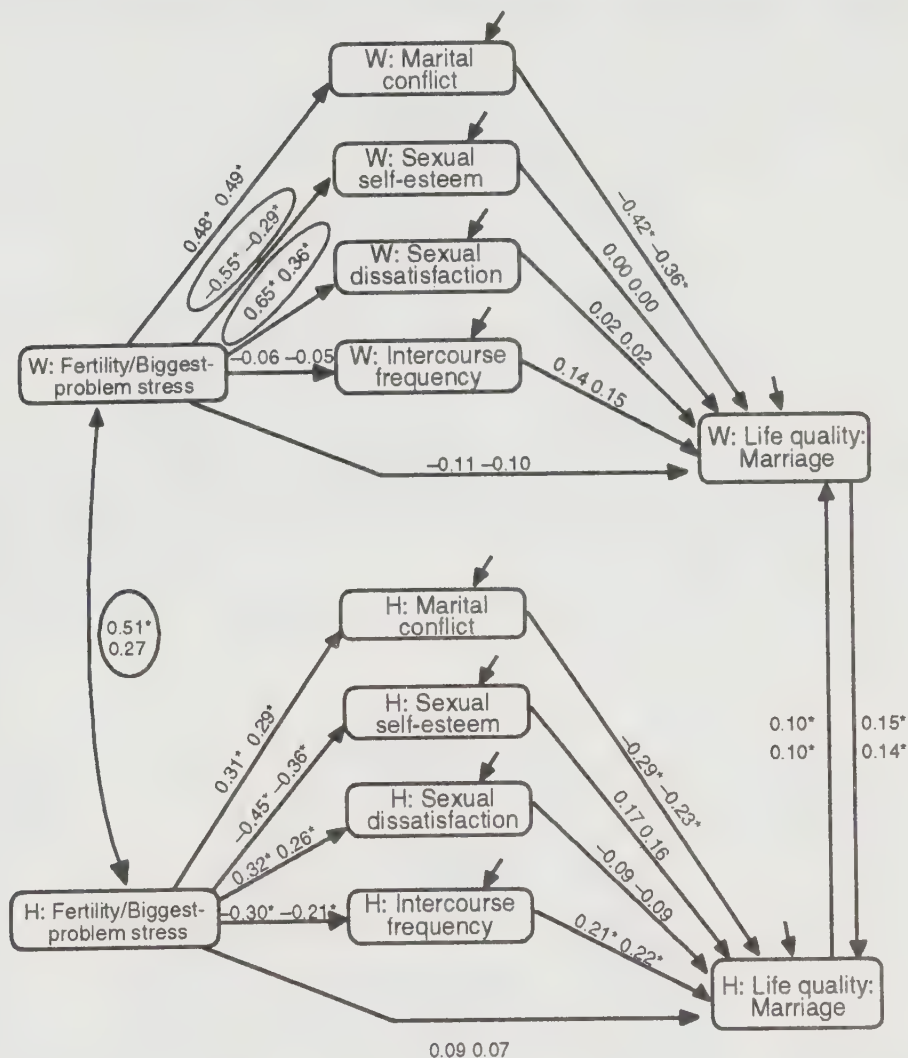
No data are perfectly valid, and the model allows for measurement error (as described in the notes to Exhibit 4A.1). The statistical results show best estimates of what causal effects would be after correcting for measurement error.

Results

This model was estimated separately, but simultaneously, for two types of couples: (1) fertility-problem couples, where the stress being assessed was specifically related to the fertility problem, and (2) presumed-fertile couples, for whom a parallel set of questions inquired about stress associated with a self-identified biggest problem. The necessary data, all of which came from Wave 1, were available for 157 couples (314 individuals) in the first group, and 82 couples (164 individuals) in the second. This same model was estimated for each of four different aspects of life quality: self-evaluations of own marriage, own health, own self-efficacy, and own life-as-a-whole. In evaluating the results of analyses such as these, one should consider the reasonableness of the parameter estimates and the fit of the results to the real world. These models do well by these criteria. As shown in the exhibits, the Comparative Fit Indices were always above 0.97; in three of the four models the discrepancies between predicted and observed values were statistically insignificant; and, despite the substantial number of cross-group equality constraints, there were few statistically significant anomalous parameter estimates.

Detailed statistical results for each of the four aspects of life quality appear in Exhibits 4A.1-4A.4, and summaries of the direct, indirect, and total effects of stress — for wives and husbands, and for fertility-problem and presumed-fertile couples — appear in Exhibit 4A.5.

Exhibit 4A.1 Causal Model for Stress Marriage Factors, and Evaluations of Marriage: Standardized Parameters for Wives and Husbands in Fertility-Problem and Presumed Fertile Couples



FIT: $\chi^2 = 63.9$, $df = 53$, $p = 0.14$, $CFI = 0.985$

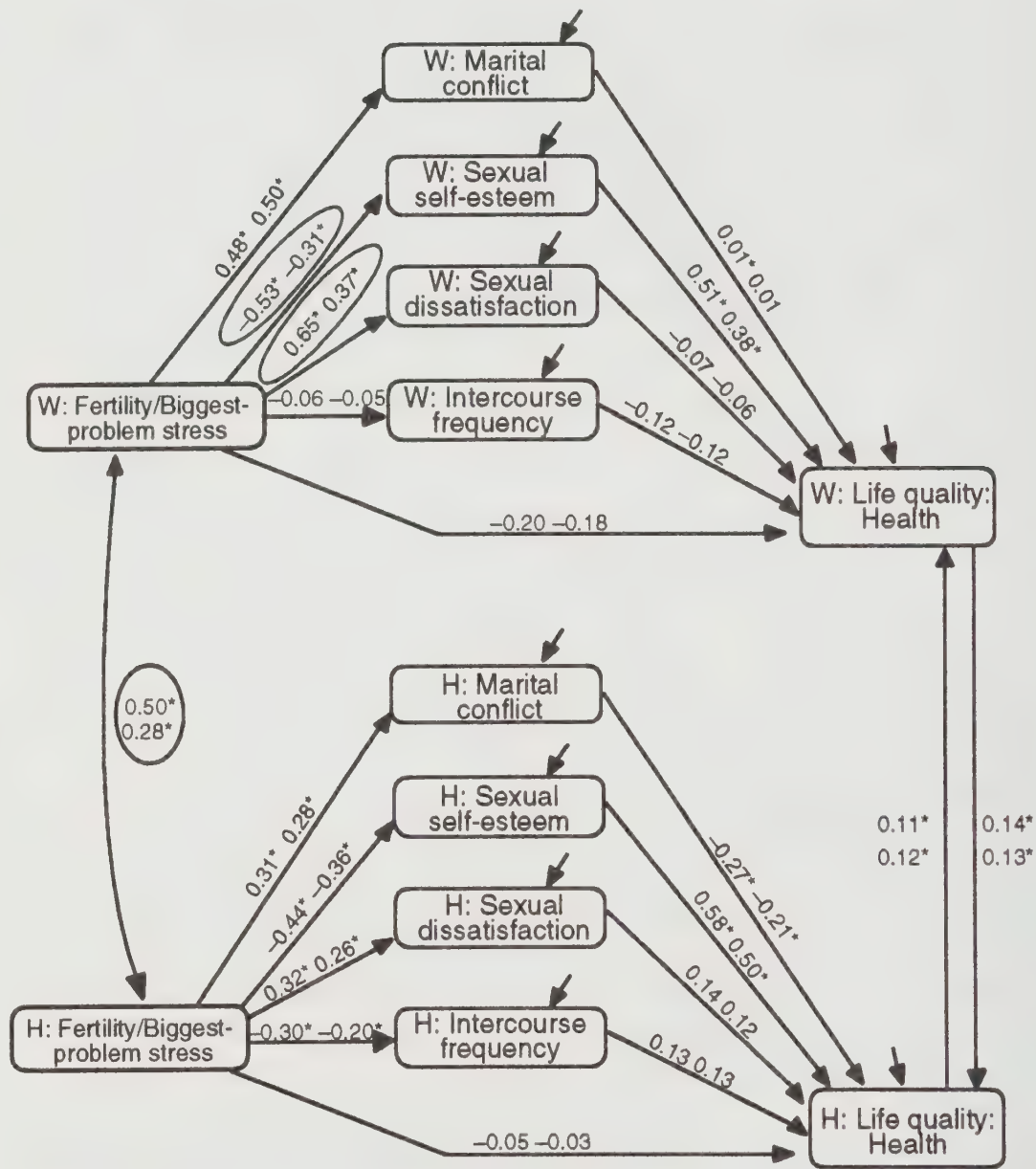
* $p < 0.05$

Notes: First number is for fertility-problem couples, second for presumed-fertile couples. Pairs of parameters within ovals are significantly different between the two groups; all others are equivalent (except for standardization). W = wife; H = husband. This exhibit follows conventions for showing causal models: one-headed arrows indicate direct effects, two-headed arrows indicate covariation for which causal effects are not specified; arrows without a labelled start indicate effects of all other (i.e., residual) causes on the target variable. All variables shown are latent; each one's link to its corresponding observed measure was equal to the square root of its reliability.

Covariances among the residual inputs to the eight marriage factors were not restricted to zero and were allowed to differ between the groups. Standardized parameters are shown for ease of interpretability; all calculations were performed using unstandardized variables.

Source: F.M. Andrews, A. Abbey, and L.J. Halman. "Is Fertility-Problem Stress Different? The Dynamics of Stress in Fertile and Infertile Couples." *Fertility and Sterility* 57 (1992), 1250. Reproduced with permission of the publisher, The American Fertility Society.

Exhibit 4A.2 Causal Model for Stress, Marriage Factors, and Evaluations of Own Health: Standardized Parameters for Wives and Husbands in Fertility-Problem and Presumed-Fertile Couples

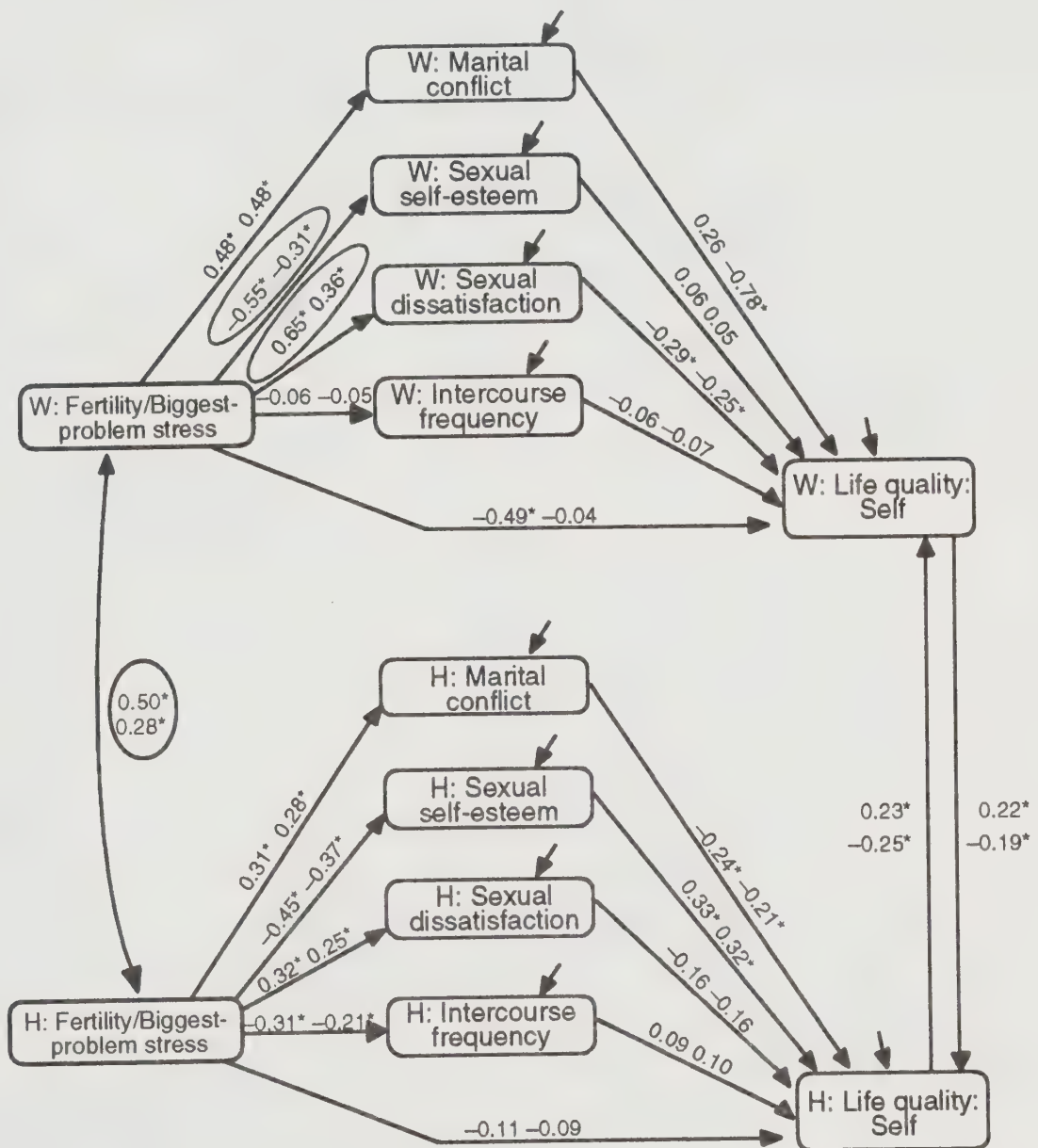


FIT: $\chi^2 = 67.2$, $df = 53$, $p = 0.09$, $CFI = 0.980$

* $p < 0.05$

Note: First number is for fertility-problem couples, second for presumed-fertile couples. Pairs of parameters within ovals are significantly different between the two groups; all others are equivalent (except for standardization).

Exhibit 4A.3 Causal Model for Stress, Marriage Factors, and Evaluations of Own Self-Efficacy: Standardized Parameters for Wives and Husbands in Fertility-Problem and Presumed-Fertile Couples

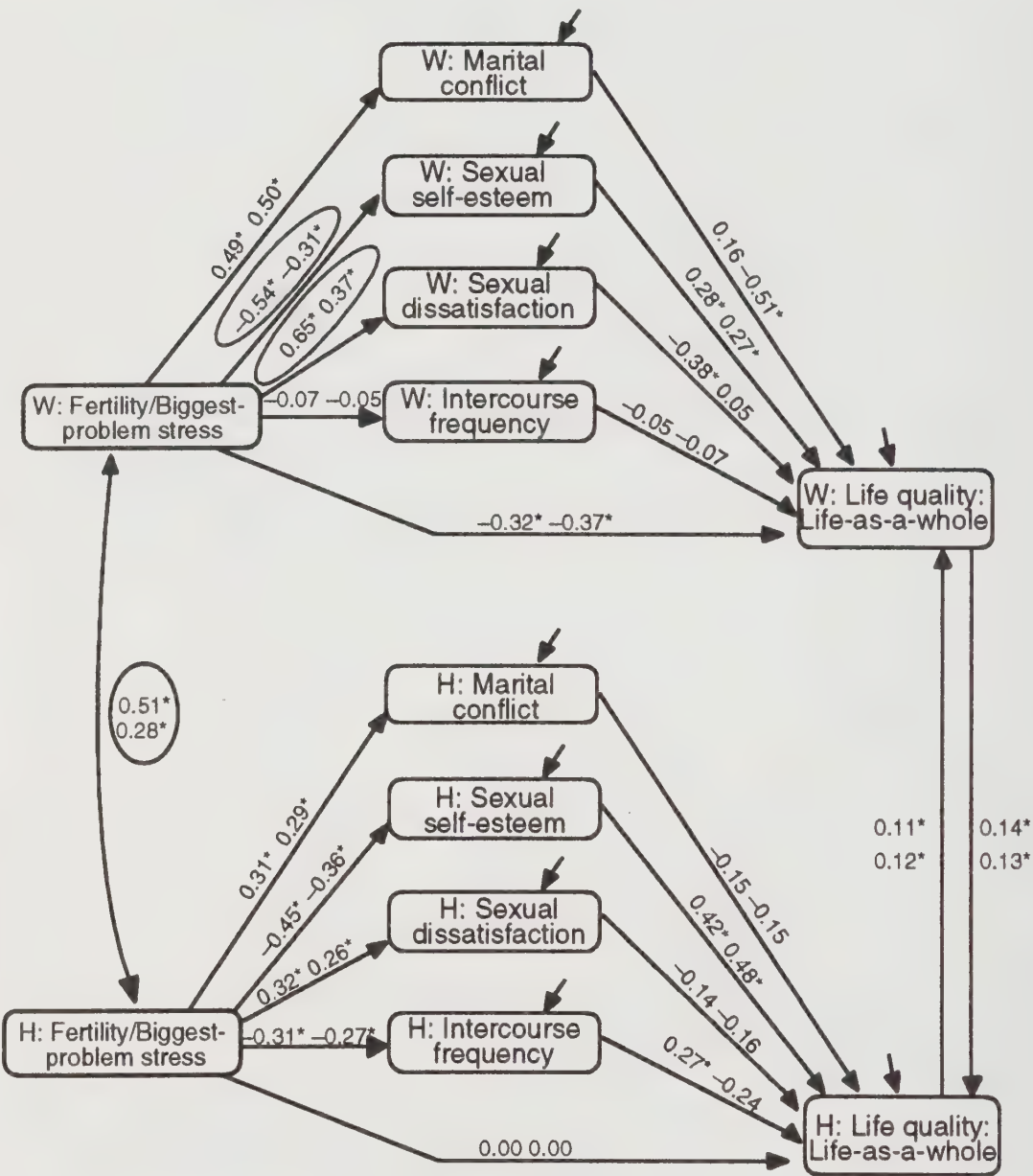


FIT: $\chi^2 = 71.6$, $df = 50$, $p = 0.02$, $CFI = 0.971$

* $p < 0.05$

Note: First number is for fertility-problem couples, second for presumed-fertile couples. Pairs of parameters within ovals are significantly different between the two groups; all others are equivalent (except for standardization).

Exhibit 4A.4 Causal Model for Stress, Marriage Factors, and Evaluations of Life-as-a-Whole: Standardized Parameters for Wives and Husbands in Fertility-Problem and Presumed-Fertile Couples



FIT: $\chi^2 = 61.1$, $df = 50$, $p = 0.14$, $CFI = 0.986$

* $p < 0.05$

Note: First number is for fertility-problem couples, second for presumed-fertile couples. Pairs of parameters within ovals are significantly different between the two groups; all others are equivalent (except for standardization).

Exhibit 4A.5 Direct, Indirect, and Total Effects of Stress from Fertility Problem or Biggest Problem for Wives and Husbands in Fertility-Problem or Presumed-Fertile Couples

	Aspect of life quality evaluated			
	Marriage	Health	Self	Life-as-a-whole
<i>Couples with a fertility problem</i>				
Wives				
Direct	-0.11	-0.20	-0.49	-0.32
Indirect	-0.20	-0.32	-0.12	-0.33
Total	-0.31	-0.52	-0.61	-0.65
Husbands				
Direct	0.09	-0.18	-0.11	0.00
Indirect	-0.26	-0.14	-0.32	-0.37
Total	-0.17	-0.32	-0.43	-0.37
<i>Couples presumed fertile</i>				
Wives				
Direct	-0.10	-0.05	-0.04	-0.37
Indirect	-0.19	-0.33	-0.50	-0.33
Total	-0.29	-0.38	-0.54	-0.70
Husbands				
Direct	0.07	-0.03	-0.09	0.00
Indirect	-0.20	-0.24	-0.25	-0.21
Total	-0.13	-0.27	-0.34	-0.21

Figures show magnitude of effects from standardized solution. Indirect effects go via marital conflict, sexual self-esteem, sexual dissatisfaction, and/or frequency of intercourse (see accompanying models).

Source: F.M. Andrews, A. Abbey, and L.J. Halman. "Is Fertility-Problem Stress Different? The Dynamics of Stress in Fertile and Infertile Couples." *Fertility and Sterility* 57 (1992), 1251. Reproduced with permission of the publisher, the American Fertility Society.

Perhaps surprisingly, for husbands, regardless of which aspect of life quality is examined, the causal dynamics operate similarly (i.e., same direction, same strength) for those with fertility problems and for those with other problems. This is not to say that husbands' lives are unaffected by fertility problems and the stress that may accompany them, but rather that the impact of a fertility problem is not fundamentally different from the impact of other problems.

For wives, however, it makes a big difference whether the problem is a fertility problem or something else. While all stresses tend to increase wives' reports of marital conflict, stress from fertility problems has especially strong negative effects on wives' own sexual identity (sexual self-esteem and sexual satisfaction) and also on their own sense of self-efficacy. Thus it appears that fertility problems are interpreted as carrying a special negative message for wives' sense of sexual identity and self-efficacy.

In addition, the impact of marital conflict is different for wives in fertility-problem couples and wives in presumed-fertile couples. The expected negative impact on wives' sense of self-efficacy and general well-being shows up strongly for the presumed-fertile wives, but wives with a fertility problem show virtually no relationship between marital conflict and their evaluations of themselves or of their life-as-a-whole. Perhaps these wives realize that the fertility problem may lead to strained relationships with their spouse and resolve to resist allowing such conflict to reduce further their already damaged sense of self-efficacy and general well-being.

If we ask whether the total effects of stress on people's life quality differ for those in fertility-problem couples and those in presumed-fertile couples, the general finding — with two interesting exceptions — is that they do not. As shown in Exhibit 4A.5, fertility-problem stress has about the same total impact on well-being as does stress from other problems. One of the exceptions occurs for wives: stress from a fertility problem affects a woman's satisfaction with her own health more than does stress from other problems. The other exception occurs for husbands: stress from a fertility problem affects a man's satisfaction with his life-as-a-whole more than does stress from other problems.

Exhibit 4A.5 also shows that (1) wives tend to be more affected by stress than husbands, whatever the source of the stress; (2) stress, whatever its source, tends to have bigger impacts on people's sense of self-efficacy and general well-being than it does on their satisfaction with their marriages; and (3) much of the impact of stress is indirect — because stress affects the marriage factors and they then affect life quality.

Summary

Both fertility-problem and biggest-problem stress had a negative impact on four different aspects of life quality. Both infertile and presumed-fertile women were more negatively affected by stress than were their husbands. The effects of fertility- and biggest-problem stress on marital factors were largely similar; an exception was that fertility-problem stress had a larger negative effect on women's sexual self-esteem and dissatisfaction than did biggest-problem stress. These results indicate that in most respects infertility has effects similar to those of other stressors, although for women infertility has particularly large negative effects on sexuality.

The Effects of Self-Esteem, Internal Control, and Interpersonal Conflict on Marital Well-Being*

Introduction

Both the general stress literature and the infertility literature suggest that self-esteem, internal control, and interpersonal conflict might affect the relationship between infertility and well-being. Self-esteem has been defined as "the extent to which one prizes, values, approves, or likes oneself" (Blascovich and Tomaka 1991, 115). High self-esteem protects people from the negative effects of stress by increasing problem-oriented coping, perceived control, and self-enhancing attributions (Taylor 1983; Tennen and Herzberger 1987).

The extent to which individuals believe that they personally determine what happens in their lives reflects their sense of internal control (Langer 1983). Research indicates that perceptions of internal control are associated with positive affect and life satisfaction (Abbey and Andrews 1985; Abramson et al. 1978; Headey et al. 1985).

Interpersonal conflict involves the communication of negative affect and a lack of caring and understanding (Abbey and Andrews 1985). Several researchers have found that interpersonal conflict with significant others is negatively associated with well-being, and is usually a stronger predictor of well-being than is social support (Abbey et al. 1985; Fiore et al. 1983).

Results

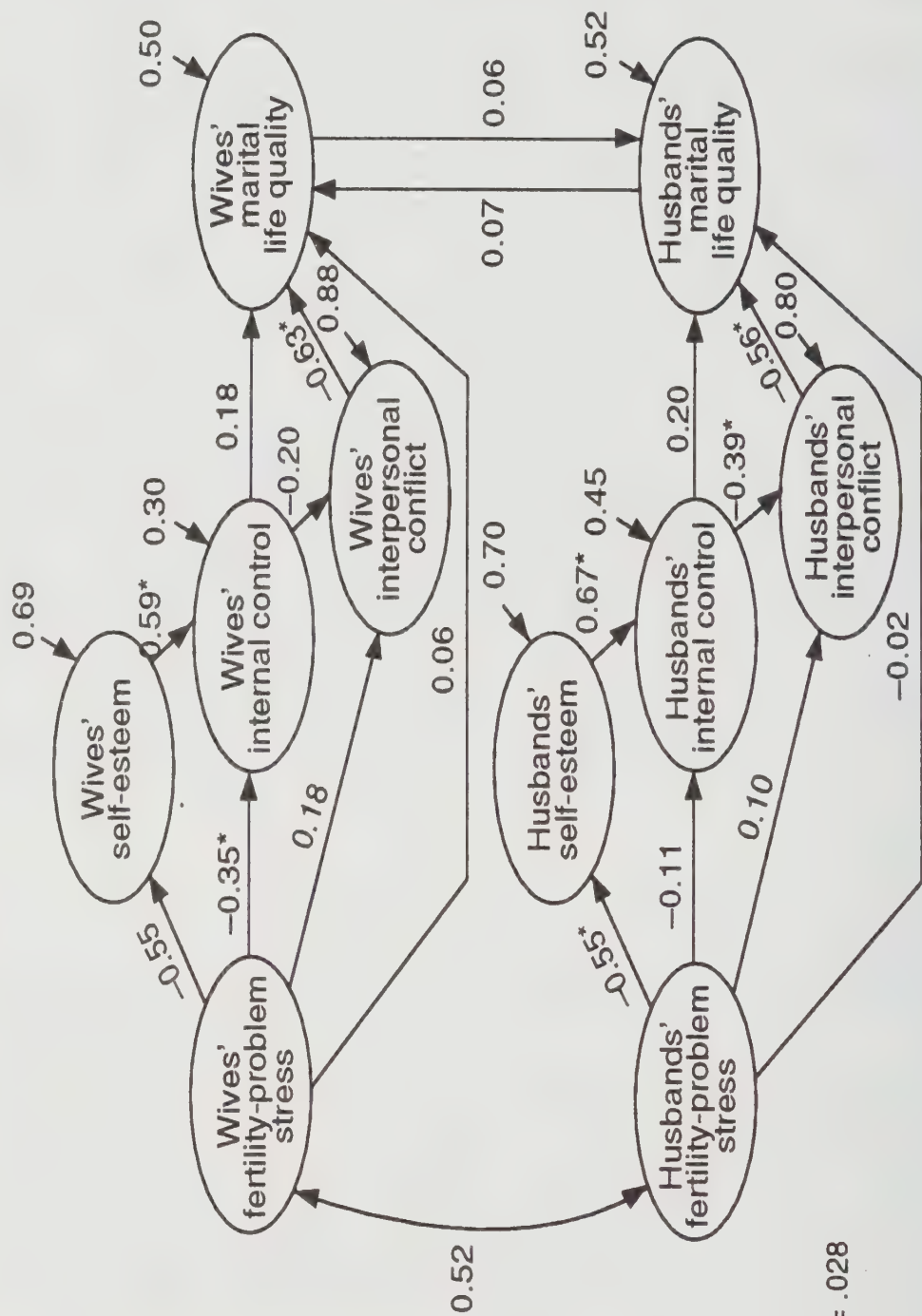
Description of Model

Exhibit 4B.1 presents the theoretical model examined in these analyses, as well as the major results. It was hypothesized that the stress produced by infertility would have direct and indirect negative effects on life quality for both women and men. Indirect effects were expected to occur via the effects of fertility-problem stress on self-esteem, perceived internal control, and interpersonal conflict with one's spouse. (Preliminary analyses, not described here, indicated that the relationships between stress, mediators, and well-being were additive rather than interactive.) While the model posits and tests a particular causal ordering among the variables, these are cross-sectional data, and longitudinal data analysis is needed to confirm these findings.

These hypotheses were examined using EQS, a specific software programme used for structural equation analysis, and involve latent variables and allowances for unreliability of measurement (Bentler 1989). All causal analyses were performed on unstandardized variance/covariance matrices to allow for possible differences between husbands and wives. To ease interpretation, parameter estimates were then converted to standardized form.

* The introduction of this paper is similar to that of a published paper, although the precise results presented come from an analysis not included in the publication: Abbey et al. (1992a).

Exhibit 4B.1 Structural Model of the Standardized Relationships Between Fertility–Problem Stress, Psychological Variables, and Marital Life Quality



$\chi^2 = 29.85$, $df = 24$, $p = 0.19$
average standardized residual = .028
comparative fit index = 0.989
* $p < 0.05$

This model allows for covariation between husbands' and wives' responses in three ways: (1) wives' and husbands' experience of fertility-problem stress is explicitly shown as covarying (note the two-headed arrow in the exhibit); (2) each spouse's self-esteem, internal control, and interpersonal conflict were hypothesized to be influenced by fertility-problem stress and "everything else" (i.e., a residual) — wives' and husbands' residuals on the same concept were allowed to covary with one another; and (3) it was hypothesized that each spouse's life quality would have a direct effect on the other spouse's life quality (note the reciprocal arrows linking these latent variables).

In addition to the structural dynamics just described, the model includes explicit allowance for the differential precision of measurement of the concepts, based on the Cronbach alphas described in the Measures section of Part 1. This allows the structural parameters, which are of primary interest, to reflect best estimates of the true effects, unconfounded by random measurement errors.

Substantive Results

Exhibit 4B.1 depicts the structural parameters. As can be seen in the exhibit, the pattern of results was similar for wives and husbands, although the magnitude of some of the parameters was larger for women than for men. As hypothesized, fertility-problem stress was negatively related to self-esteem and internal control and positively related to interpersonal conflict for both sexes. Self-esteem was highly and positively related to internal control, which in turn was moderately and negatively related to interpersonal conflict.

Also as predicted, self-esteem and internal control were positively related to marital life quality. The association of self-esteem with life quality occurred indirectly, via its relationship to internal control. Interpersonal conflict was directly and negatively related to marital life quality. Each spouse's life quality had a small, insignificant positive relationship to his or her partner's life quality (these reciprocal effects were constrained equally).

Contrary to prediction, fertility-problem stress did not have a significant direct effect on marital life quality. However, the indirect effects of fertility-problem stress were substantial (-0.32 for wives, -0.25 for husbands). Thus, fertility-problem stress exerted its negative effects on life quality via its effects on self-esteem, internal control, and interpersonal conflict. Also, fertility-problem stress had a somewhat larger impact on women's marital life quality than on men's.

As can be seen by the information provided on the exhibit, the fit of the model was good. The mean absolute standardized residuals were low, the comparative fit index was high, and, as one desires with structural modelling analyses, the chi square values were not statistically significant. About 50 percent of the variance in marital life quality was explained.

Summary

As hypothesized, the stress associated with infertility had deleterious effects on women's and men's marital life quality. The impact of fertility-problem stress on well-being was largely mediated by self-esteem, internal control, and interpersonal conflict. The greater the fertility-problem stress, the lower men's and women's self-esteem and internal control and the greater their interpersonal conflict.

Part 5. Changes in Psychosocial Factors Associated with Changes in Parental Status**Introduction**

The exhibits in this chapter show some of the initial results we found when we examined trends in psychosocial factors over the three sets of interviews of our study and classified people according to their fertility status at the first interview, their parental status at the third interview, and their gender. The key question is, how does change in parental status relate to changes in psychosocial factors?

The exhibits are a little hard to read and reflect the early stage of our analysis in this area. We will be doing considerable further work in this area. However, even in this preliminary form, some very interesting trends stand out.

Before considering the trends, let us recall the basic design of our study that makes this analysis possible. At interviews conducted in 1988 we obtained information separately from both wives and husbands in two types of couples — those attempting to cope with a fertility problem and those who were presumed to be fertile. Nearly all of these couples were interviewed again in 1989, and again in 1990.

By 1990, some of the couples had become parents through either birth or adoption, other couples were not parents (and the wife was not pregnant), and in some couples the wife was then pregnant. The non-parents were further classified into three subgroups: (a) presumed fertile and were not (yet) trying for a child; (b) had a fertility problem and were still trying for a biological child; and (c) had a fertility problem and had given up trying for a biological child.

The group labels shown for the three panels of Exhibit 5.1 indicate the 16 groups that the above classifications produce and the numbers of cases available in each. Note that the number of cases from couples where the wife was pregnant is quite small; accordingly, we do not include these small groups in all analyses.

Results

Number of Children Expected

Exhibit 5.1 shows trends in the number of children couples expected to have eventually. The findings are straightforward and not surprising, and they increase our confidence that the groups we have isolated behave as expected. The dominant trend for people who became parents (Exhibit 5.1, first panel) is an increase in the number of children they expected to have. The major exception, quite reasonably, is shown by fertility-problem wives who became parents by adopting a child. All of the subgroups from couples where the wife was pregnant also show this same general trend — higher estimates for number of children at Wave 3 than at Wave 1. In notable contrast are all of the subgroups of non-parents at Wave 3 (Exhibit 5.1, second panel). They all show at least slight declines from Wave 1 to Wave 3. The decline is especially sharp, as one might expect, for wives who had a fertility problem and had given up trying for a biological child.

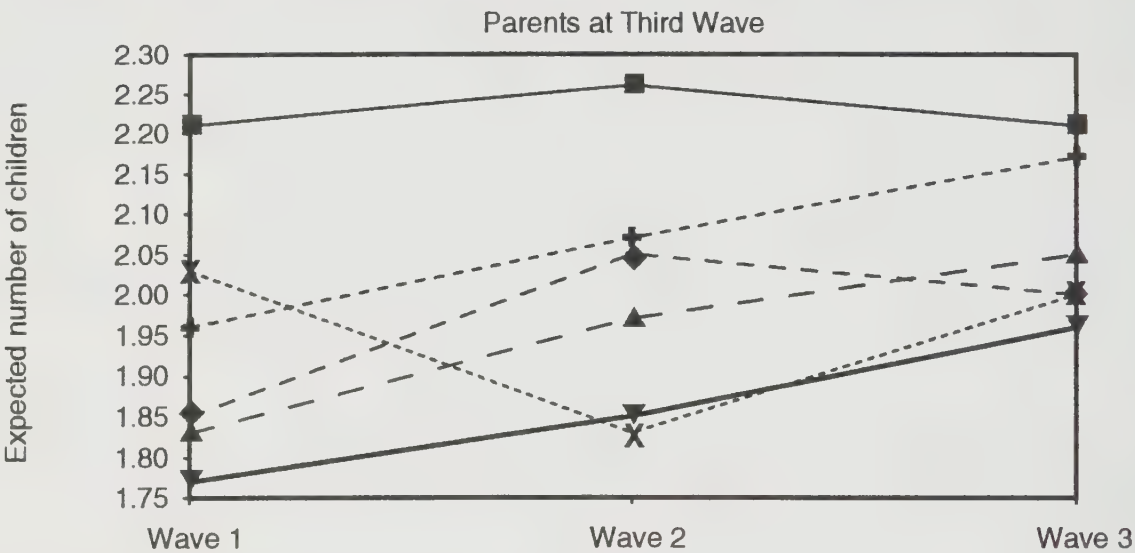
Amount of Stress

Exhibit 5.2 shows changes in stress over the course of the three waves. For couples with a fertility problem, the stress was specifically that associated with coping with the fertility problem. For other couples, it was stress associated with whatever they identified as their biggest problem. (Accordingly, for couples who had a fertility problem at Wave 1 and had had a child by Wave 3, the stress was fertility-problem stress at Wave 1 and biggest-problem stress at Wave 3.)

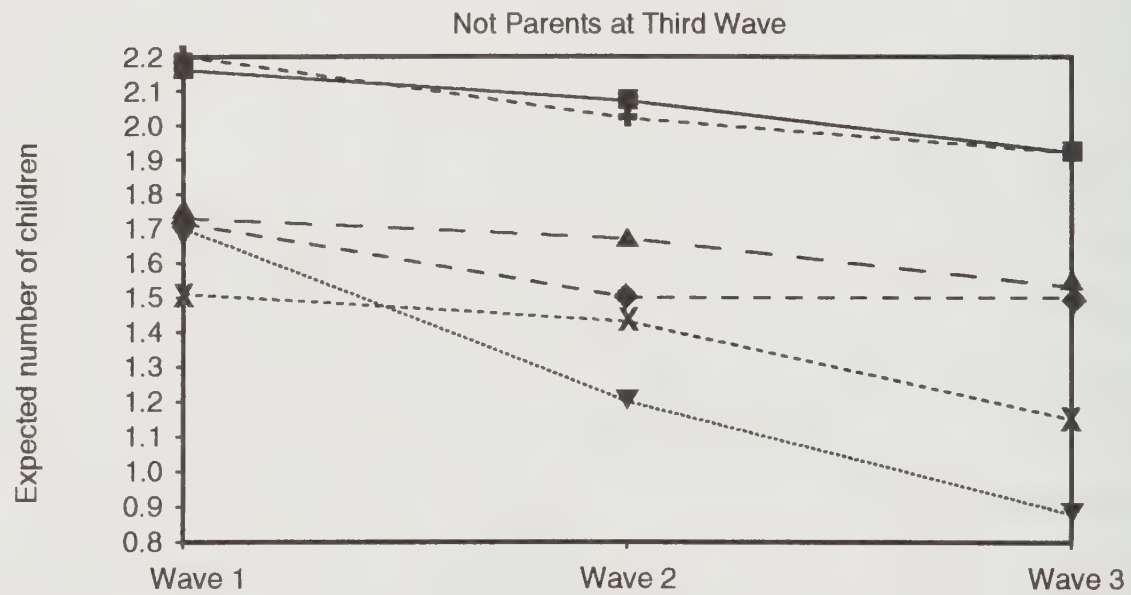
The trends in the top panel of Exhibit 5.2 are striking. Among wives who had a fertility problem but had become parents by Wave 3, stress levels started very high (compared to other groups) and dropped sharply. This was true for both those who had a live birth and those who adopted a child. In contrast, most other groups of individuals who became parents — husbands and wives who were initially presumed fertile — did not show marked changes in stress between Waves 1 and 3.

In the lower panel of Exhibit 5.2 are trends for non-parents. Stress was high, and stayed high, for fertility-problem wives who were still trying to have a child. But stress levels were lower at Wave 3 than at Wave 1 for both wives and husbands who started at Wave 1 with a fertility problem but who had given up trying for a biological child by Wave 3. This demonstrates an important adjustment that people in these couples were able to make. Once they had given up, they came to grips with their lives, adjusted their expectations, and then identified as their “biggest problem” something that caused much less stress than their former fertility problem.

Exhibit 5.1 Expected Number of Children at Waves 1, 2, 3 by Gender, Whether Had Fertility Problem, and Parental Status at Wave 3

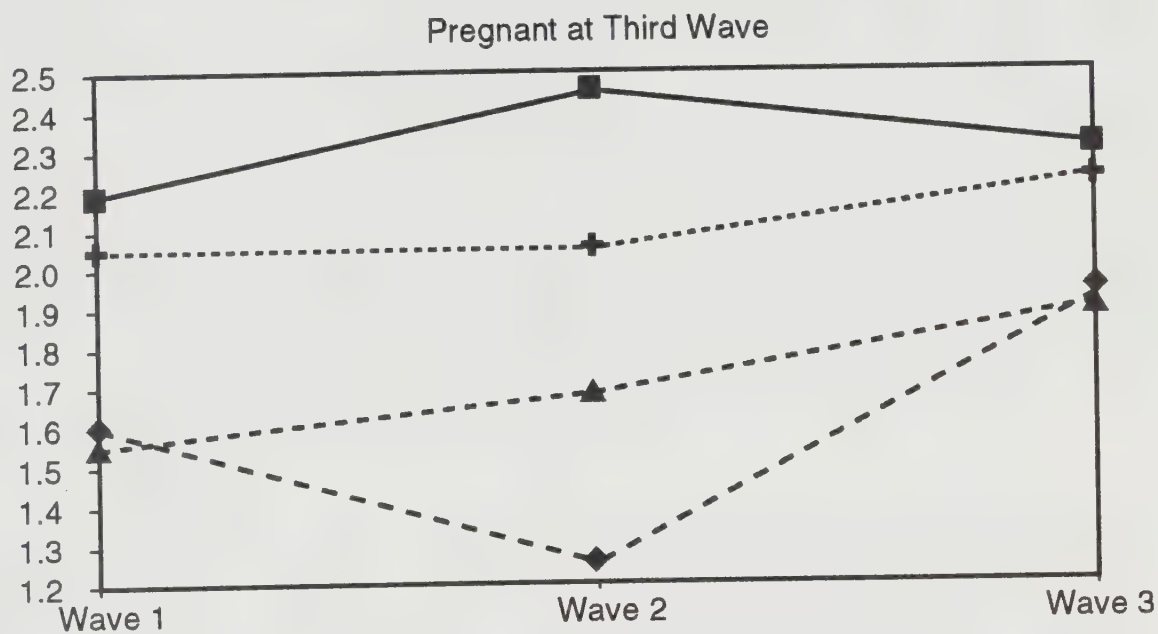


- Husbands, fertile parents by birth (m=27)
- + Wives, fertile parents by birth (27)
- ◆ Husbands, fertility problem parents by birth (61)
- ▲ Wives, fertility problem parents by birth (61)
- X Husbands, fertility problem parents by adoption (14)
- ▼ Wives, fertility problem parents by adoption (14)



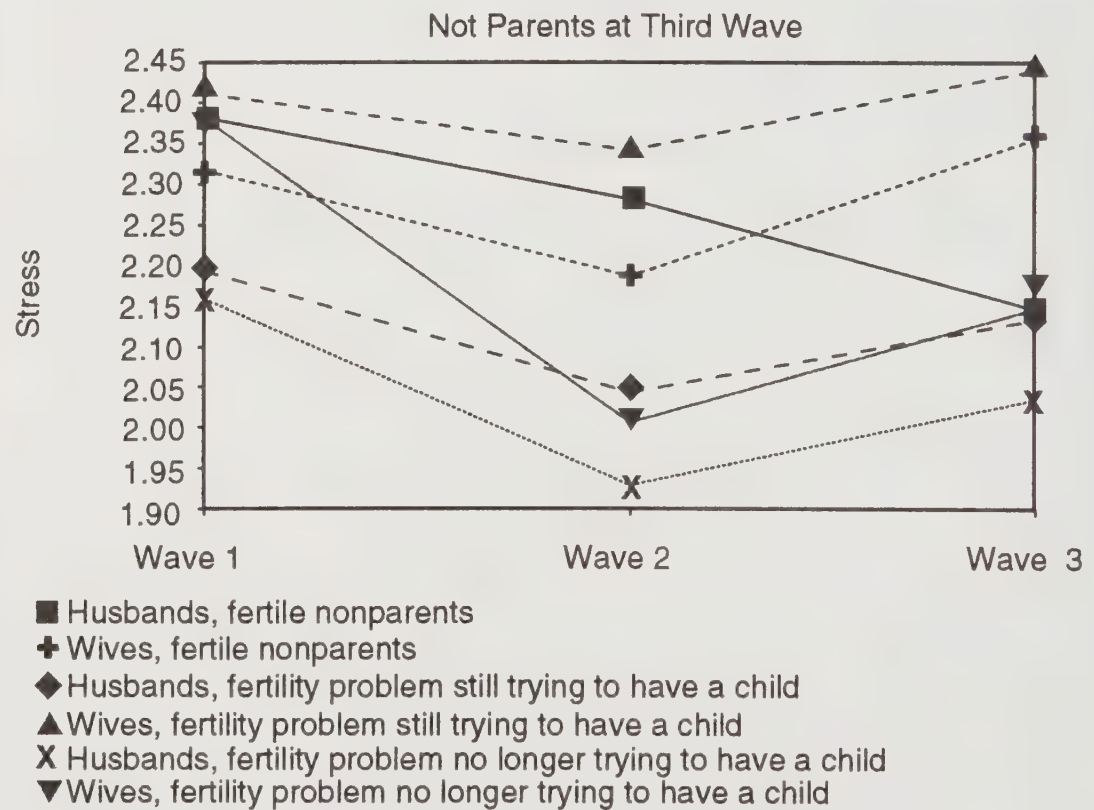
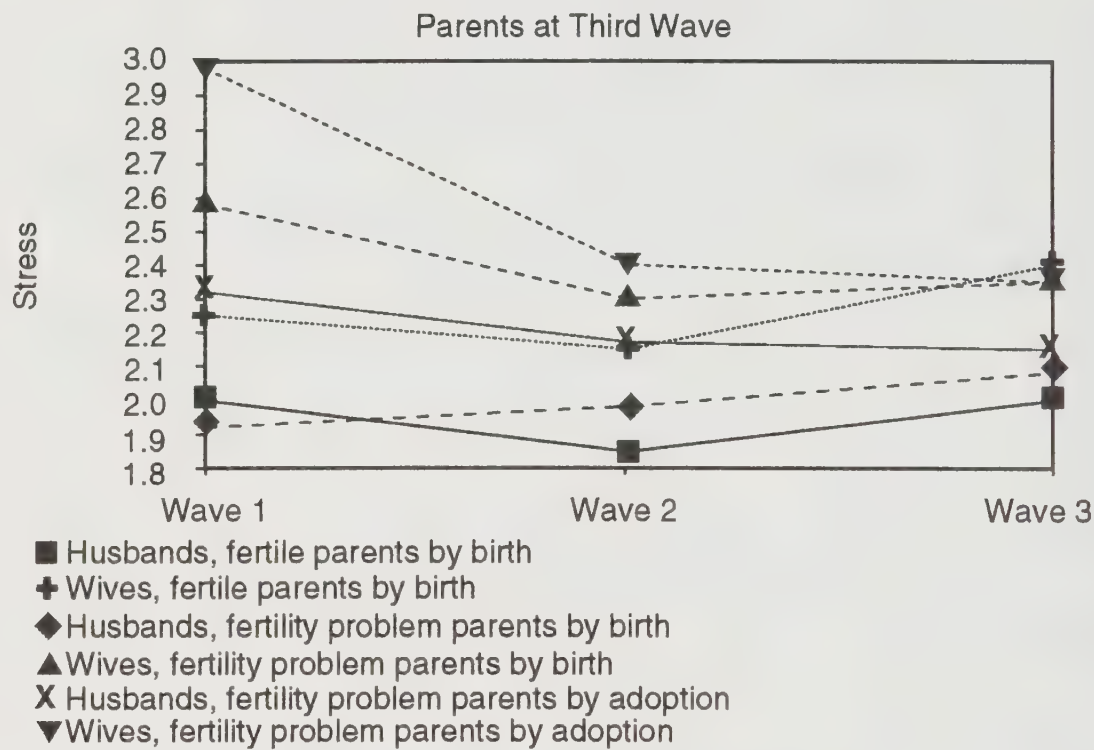
- Husbands, fertile nonparents (n=40)
- + Wives, fertile nonparents (40)
- ◆ Husbands, fertility problem still trying to have a child (85)
- ▲ Wives, fertility problem still trying to have a child (85)
- X Husbands, fertility problem no longer trying to have a child (85)
- ▼ Wives, fertility problem no longer trying to have a child (85)

Exhibit 5.1 (Cont'd)



- Husbands, fertile (n=7), wife pregnant
- + Wives, fertile (7), wife pregnant
- ◆ Husbands, fertility problem (9), wife pregnant
- ▲ Wives, fertility problem (9), wife pregnant

Exhibit 5.2 Fertility Problem or Biggest-Problem Stress at Waves 1, 2, 3 by Gender, Whether Had Fertility Problem, and Parental Status at Wave 3



Global Well-Being

Exhibit 5.3 contains results on global well-being. This is our most general measure of life quality. It tends to show patterns that are similar to many of the more specific measures.

The general pattern for people who became parents is that evaluations of global well-being were either stable or rose modestly between Waves 1 and 3. That is also true for those who had a fertility problem and gave up trying to have a biological child. Note, particularly, the very sharp rise for this group of husbands. In contrast, fertility-problem wives who were still trying to have a child at Wave 3 showed sharp decreases in global well-being.

The third panel of Exhibit 5.3, which shows changes in global well-being for couples who were pregnant at Wave 3, shows huge increases in the reports from the pregnant wives, both those who were initially presumed fertile and especially those who started with a fertility problem. Life seemed good to these pregnant wives! As can be seen, their husbands showed more stable reports of well-being.

Home Life Stress

In addition to our general stress measure, which taps stress linked to either the fertility problem or the self-identified biggest problem, we also asked specifically about home life stress. Changes in home life stress appear in Exhibit 5.4 and show some clear patterns.

All groups who became parents (Exhibit 5.4, upper panel) showed increases in home life stress. Although new babies may contribute to the parents' sense of global well-being, as discussed just above, these data show a pattern familiar to most parents — new babies also may increase stress at home. Husbands in fertility-problem couples who adopted a child showed particularly strong increases in home life stress.

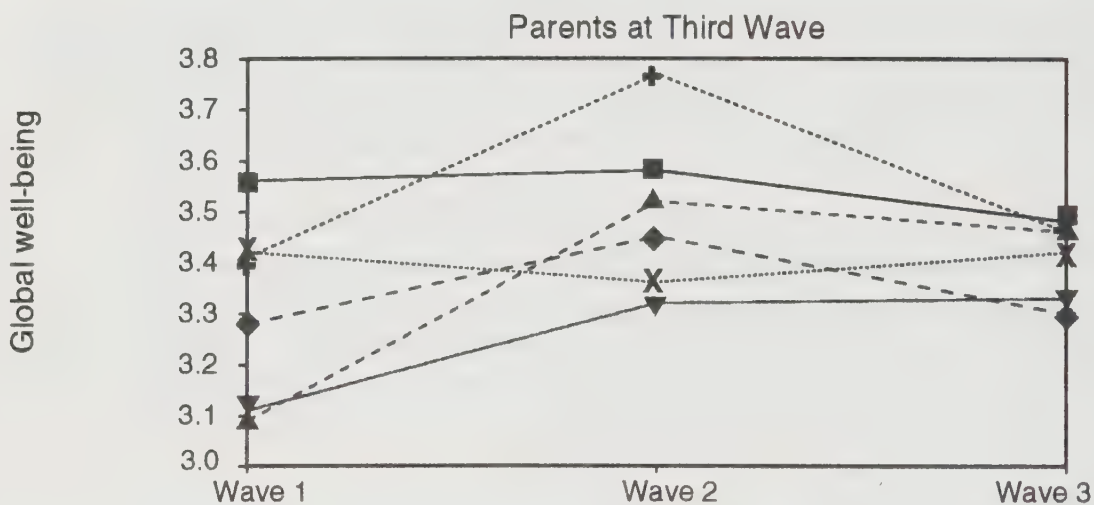
In contrast, many (not all) of the groups that had not become parents by Wave 3 (Exhibit 5.4, lower panel) showed flatter trends. Husbands in fertility-problem couples that gave up actually showed a decrease in home life stress, but fertility-problem wives who were still trying showed an increase.

Self-Esteem

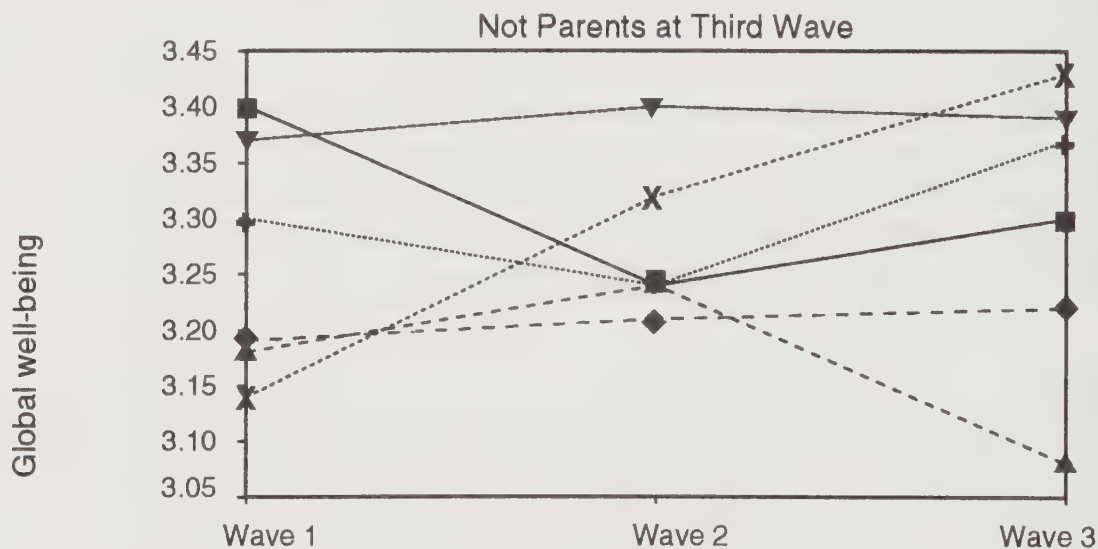
Exhibit 5.5 shows data for self-esteem at Waves 1, 2, and 3. Most of the trends show mild increases or stability if one compares Waves 1 and 3, and there are few striking differences between groups.

However, there are some very interesting differences between levels of self-esteem at Wave 3. Note that among parents (Exhibit 5.5, upper panel), the lowest self-esteem was reported by both wives and husbands who had had fertility problems and then adopted a child. It seems that adoption may carry some threats to one's self-esteem, at least in the short run. In contrast, both wives and husbands who had had a fertility problem and then gave up trying to have a biological child showed the highest self-esteem among the non-parents (Exhibit 5.5, lower panel). Once again, one sees evidence of substantial psychosocial "recovery" on the part of fertility-problem couples who made a conscious decision to give up trying.

Exhibit 5.3 Global Well-Being at Waves 1, 2, 3 by Gender, Whether Had Fertility Problem, and Parental Status at Wave 3

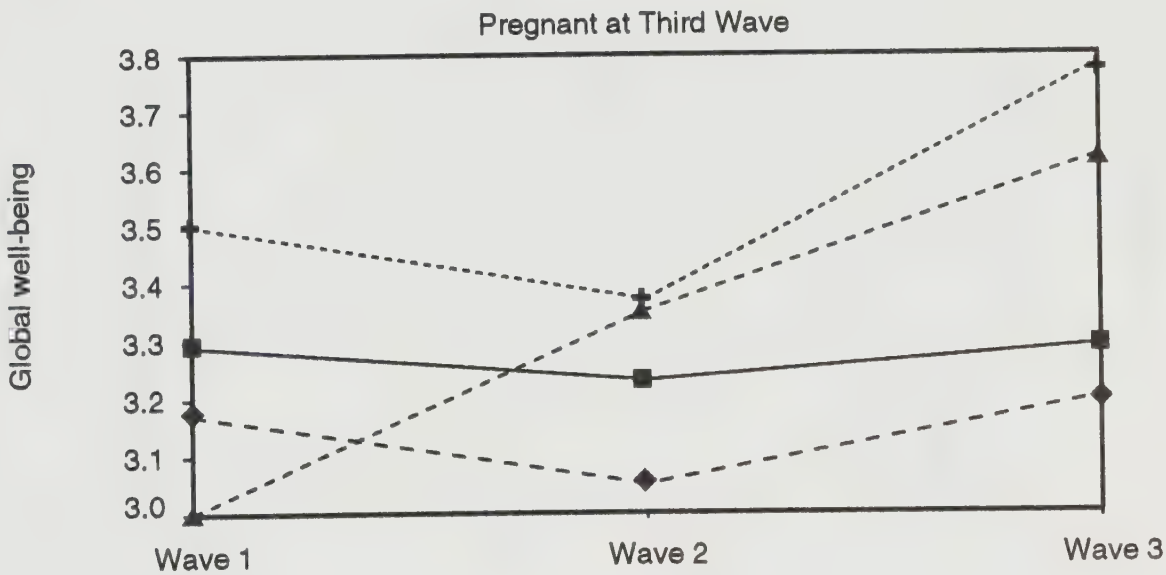


- Husbands, fertile parents by birth
- + Wives, fertile parents by birth
- ◆ Husbands, fertility problem parents by birth
- ▲ Wives, fertility problem parents by birth
- X Husbands, fertility problem parents by adoption
- ▼ Wives, fertility problem parents by adoption



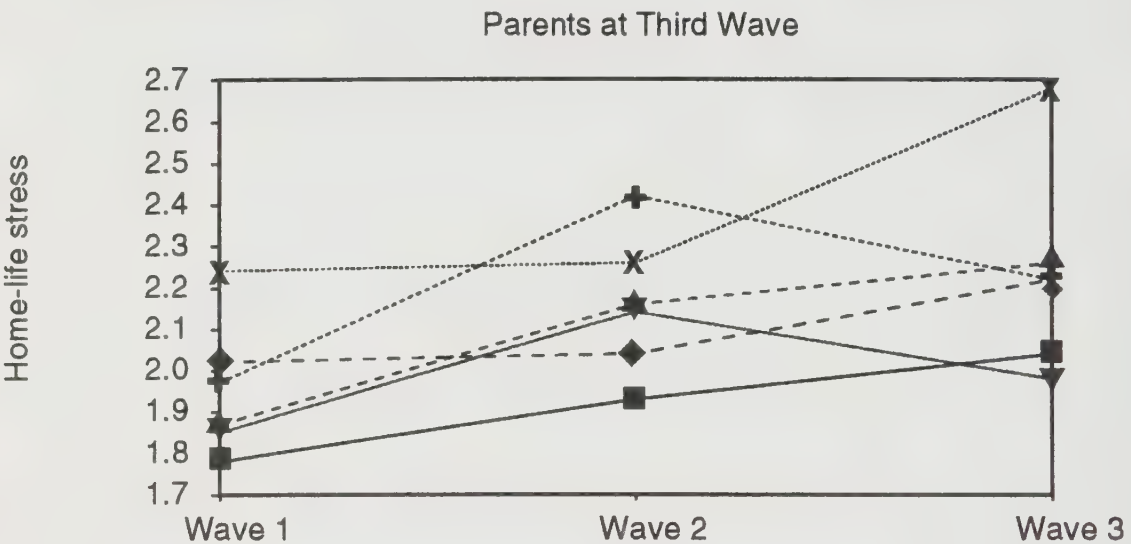
- Husbands, fertile nonparents
- + Wives, fertile nonparents
- ◆ Husbands, fertility problem still trying to have a child
- ▲ Wives, fertility problem still trying to have a child
- X Husbands, fertility problem no longer trying to have a child
- ▼ Wives, fertility problem no longer trying to have a child

Exhibit 5.3 (Cont'd)

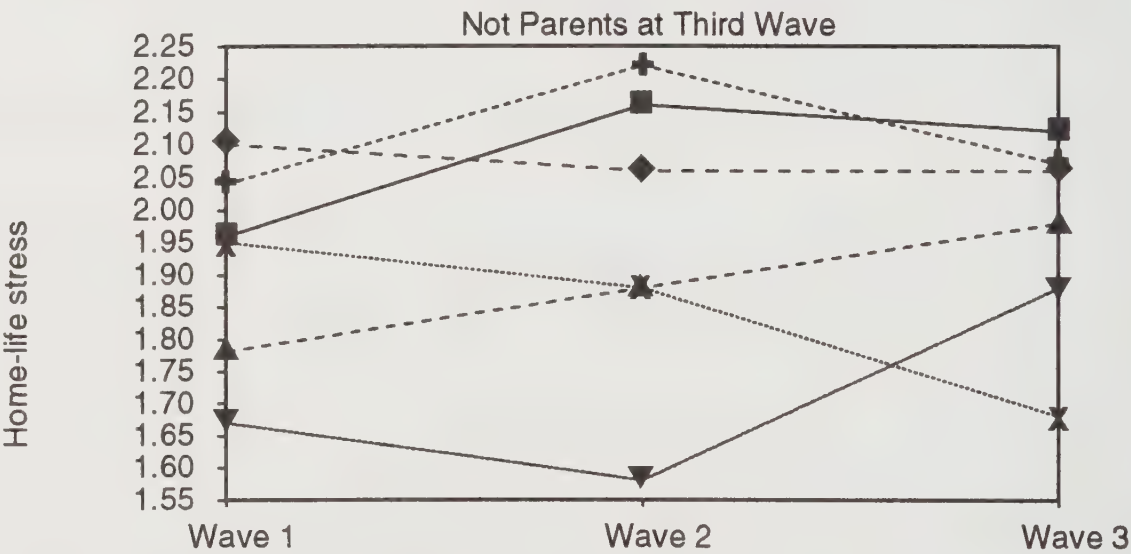


- Husbands, fertile, wife pregnant
- + Wives, fertile, wife pregnant
- ◆ Husbands, fertility problem, wife pregnant
- ▲ Wives, fertility problem, wife pregnant

Exhibit 5.4 Home-Life Stress at Waves 1, 2, 3 by Gender, Whether Had Fertility Problem, and Parental Status at Wave 3

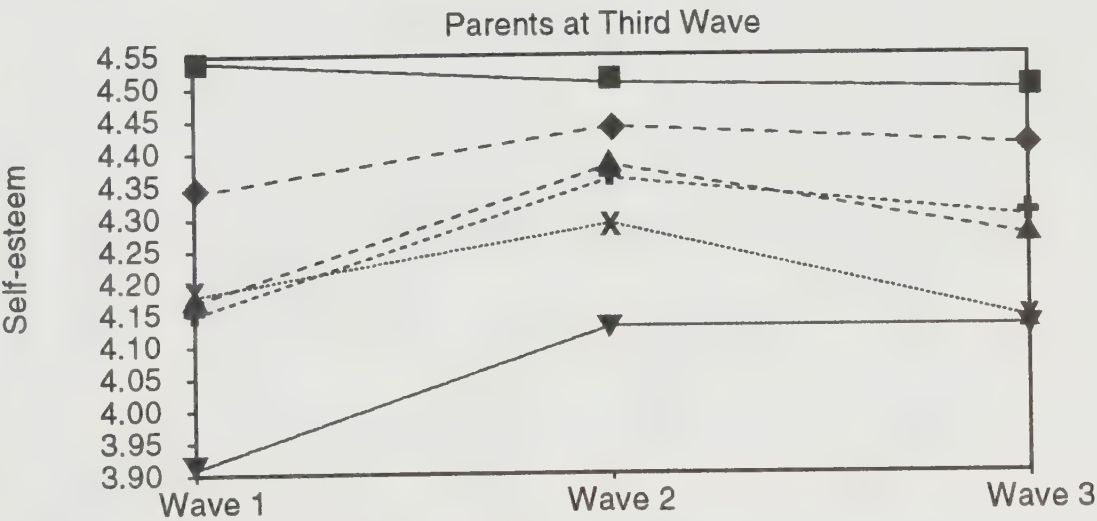


- Husbands, fertile parents by birth
- + Wives, fertile parents by birth
- ◆ Husbands, fertility problem parents by birth
- ▲ Wives, fertility problem parents by birth
- X Husbands, fertility problem parents by adoption
- ▼ Wives, fertility problem parents by adoption

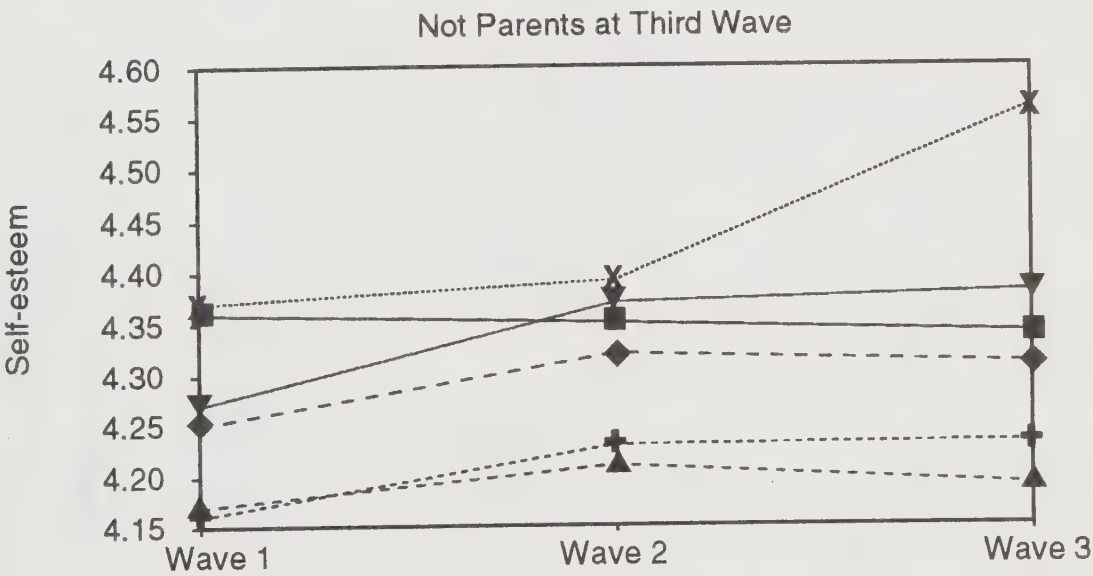


- Husbands, fertile nonparents
- + Wives, fertile nonparents
- ◆ Husbands, fertility problem still trying to have a child
- ▲ Wives, fertility problem still trying to have a child
- X Husbands, fertility problem no longer trying to have a child
- ▼ Wives, fertility problem no longer trying to have a child

Exhibit 5.5 Self-Esteem at Waves 1, 2, 3 by Gender, Whether Had Fertility Problem, and Parental Status at Wave 3

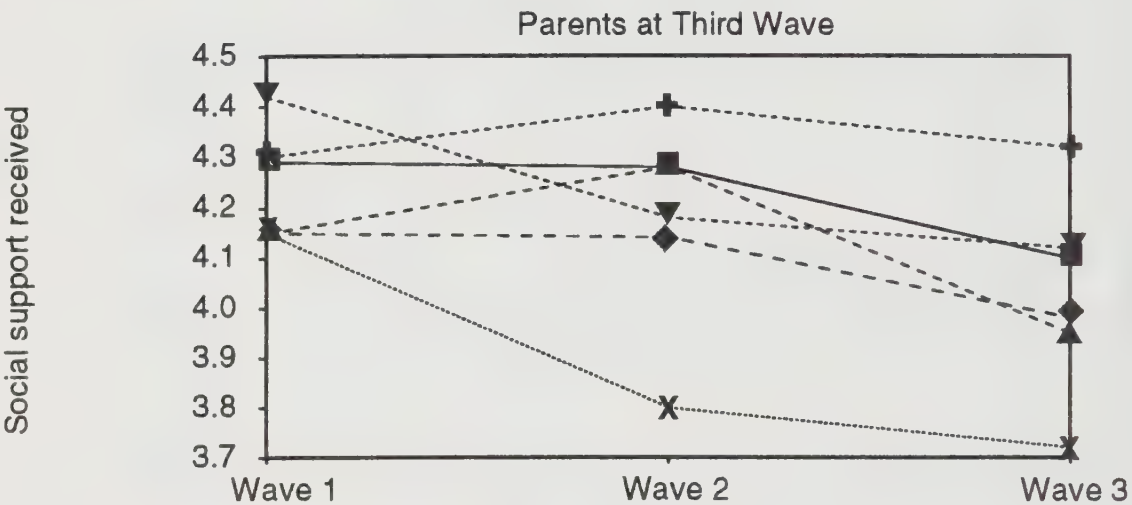


- Husbands, fertile parents by birth
- + Wives, fertile parents by birth
- ◆ Husbands, fertility problem parents by birth
- ▲ Wives, fertility problem parents by birth
- X Husbands, fertility problem parents by adoption
- ▼ Wives, fertility problem parents by adoption

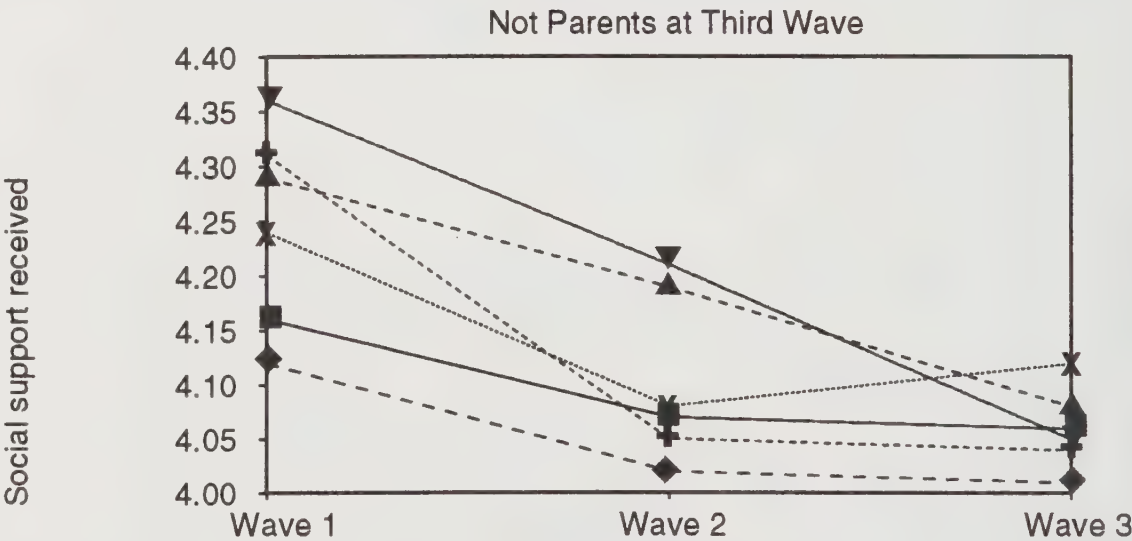


- Husbands, fertile nonparents
- + Wives, fertile nonparents
- ◆ Husbands, fertility problem still trying to have a child
- ▲ Wives, fertility problem still trying to have a child
- X Husbands, fertility problem no longer trying to have a child
- ▼ Wives, fertility problem no longer trying to have a child

Exhibit 5.6 Social Support Received (Caring) at Waves 1, 2, 3 by Gender, Whether Had Fertility Problem, and Parental Status at Wave 3

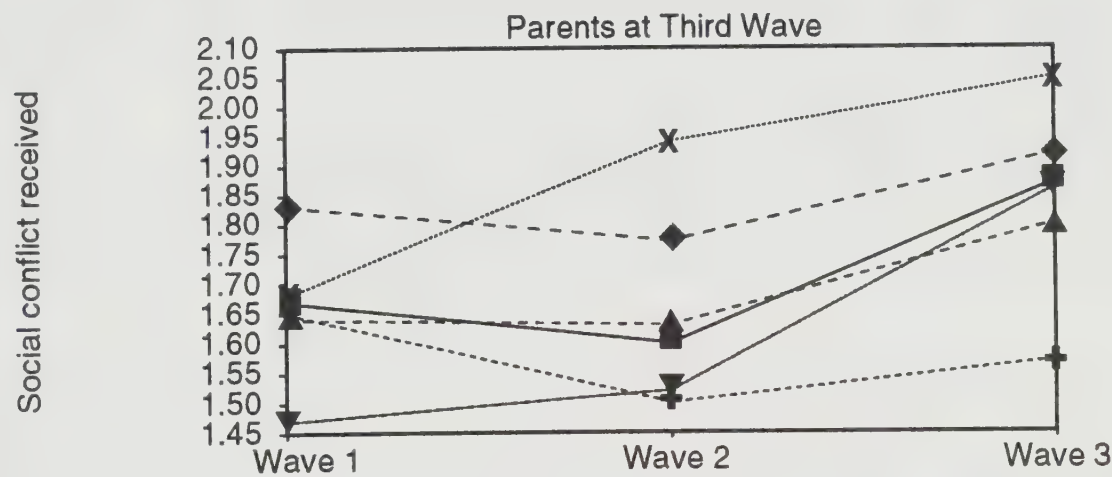


- Husbands, fertile parents by birth
- + Wives, fertile parents by birth
- ◆ Husbands, fertility problem parents by birth
- ▲ Wives, fertility problem parents by birth
- X Husbands, fertility problem parents by adoption
- ▼ Wives, fertility problem parents by adoption

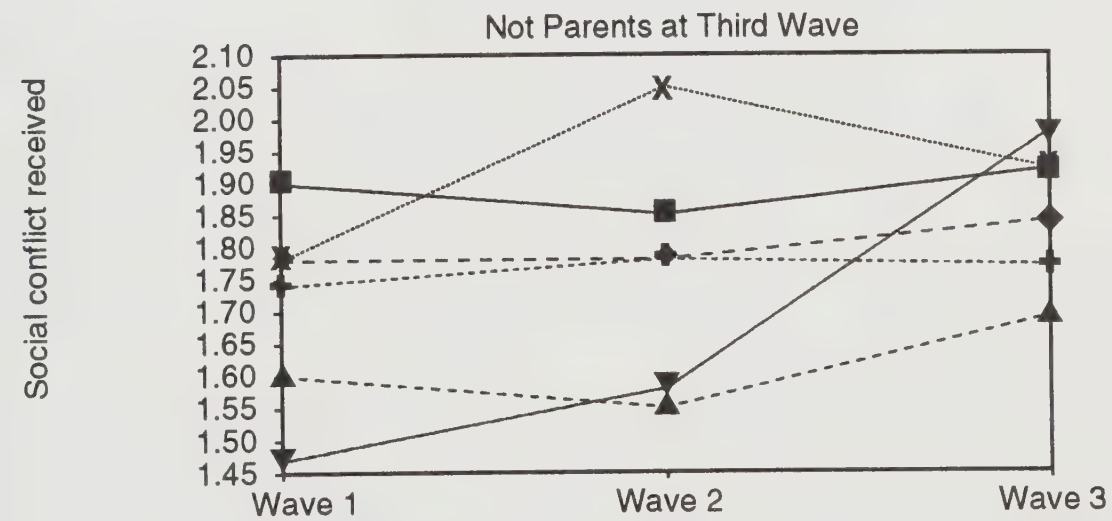


- Husbands, fertile nonparents
- + Wives, fertile nonparents
- ◆ Husbands, fertility problem still trying to have a child
- ▲ Wives, fertility problem still trying to have a child
- X Husbands, fertility problem no longer trying to have a child
- ▼ Wives, fertility problem no longer trying to have a child

Exhibit 5.7 Social Conflict Received (Negative Effect) at Waves 1, 2, 3 by Gender, Whether Had Fertility Problem, and Parental Status at Wave 3



- Husbands, fertile parents by birth
- + Wives, fertile parents by birth
- ◆ Husbands, fertility problem parents by birth
- ▲ Wives, fertility problem parents by birth
- X Husbands, fertility problem parents by adoption
- ▼ Wives, fertility problem parents by adoption



- Husbands, fertile nonparents
- + Wives, fertile nonparents
- ◆ Husbands, fertility problem still trying to have a child
- ▲ Wives, fertility problem still trying to have a child
- X Husbands, fertility problem no longer trying to have a child
- ▼ Wives, fertility problem no longer trying to have a child

Social Support and Social Conflict

Exhibits 5.6 and 5.7 show changes in social support and social (interpersonal) conflict, respectively, over the course of our study. We were surprised by both sets of findings and do not have a compelling theoretical explanation for them. Many groups reported decreases in social support from their spouses and increases in social conflict with their spouses. Surprisingly, this occurred for both those who became parents and those who did not.

Importance of Children

Exhibit 5.8 shows some fascinating and important results concerning changes in the importance people attached to having children. The message here is that people adjusted their attitudes to fit their achieved situation.

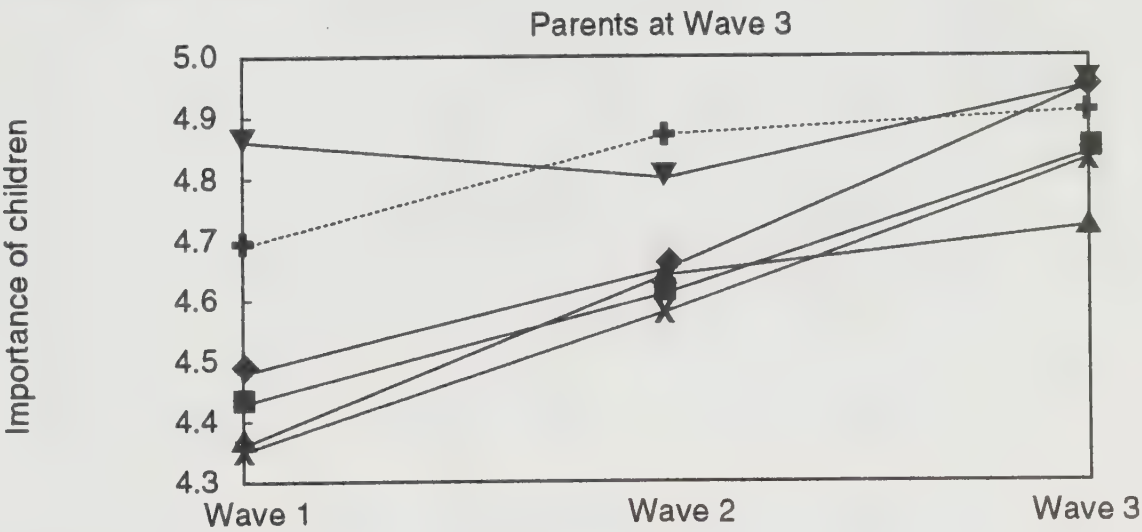
All the groups who became parents by the third interview showed increases in the importance they attached to having children relative to what they had told us at the first interview. This was also true for most of the groups where the wife was pregnant. In contrast, for those who did not become parents by Wave 3, the importance attached to having children stayed about stable or declined. The group that showed the biggest decline, perhaps as one might expect, was fertility-problem wives who had given up trying to have a biological child. They rated children as being much less important at interview three than they had at interview one, when they were actively trying to have a child.

Confidence in Having a Biological Child

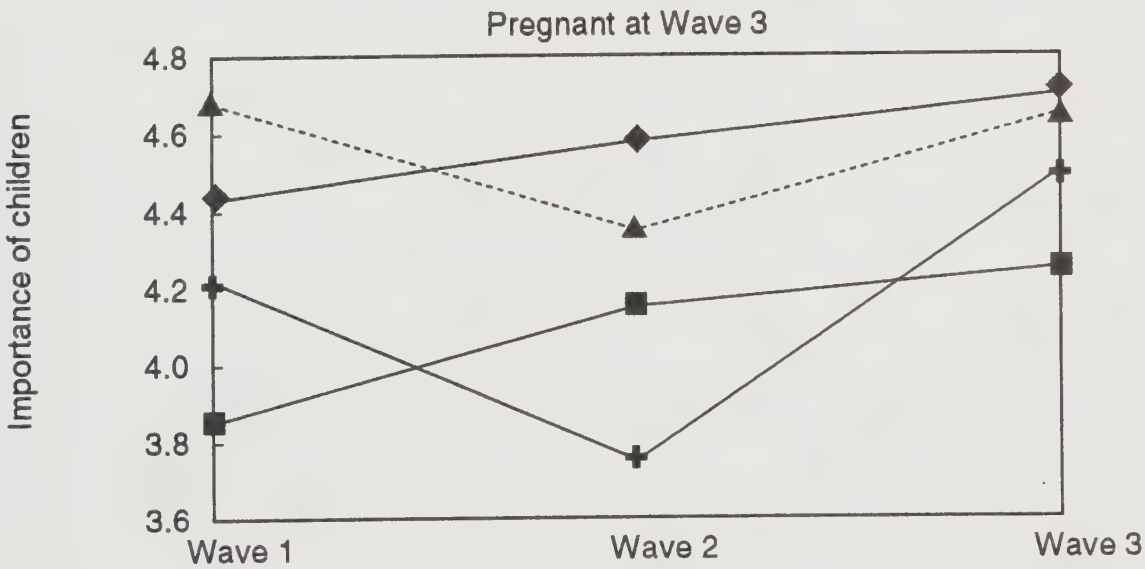
Finally, Exhibit 5.9 presents one other piece of trend data — information on confidence in being able to give birth to a biological child. These data come only from individuals in fertility-problem couples. At Wave 1, members of couples who ultimately adopted a child or gave up trying to have a biological child had less confidence than those who subsequently had a live birth, became pregnant, or were still trying at Wave 3. Thus there is evidence that those who ultimately gave up or who adopted suspected their fertility problems were more difficult to solve even at the beginning of our study.

Furthermore, the changes in the confidence shown by some of these individuals over the course of the study are striking (and reasonable). Both those who were still trying at the third interview and those who had given up trying for a biological child showed lower confidence than they had at the first interview, and the drop was much greater for those who gave up.

Exhibit 5.8 Importance of Children at Waves 1, 2, 3 by Gender, Whether Had Fertility Problem, and Parental Status at Wave 3



- Husbands, fertile parents by birth
- ◆ Wives, fertile parents by birth
- X Husbands, fertility problem parents by birth
- + Wives, fertility problem parents by birth
- ▲ Husbands, fertility problem parents by adoption
- ▼ Wives, fertility problem parents by adoption



- Husbands, fertile wife pregnant
- ◆ Wives, fertile wife pregnant
- + Husbands, fertility problem
- ▲ Wives, fertility problem

Exhibit 5.8 (cont'd)

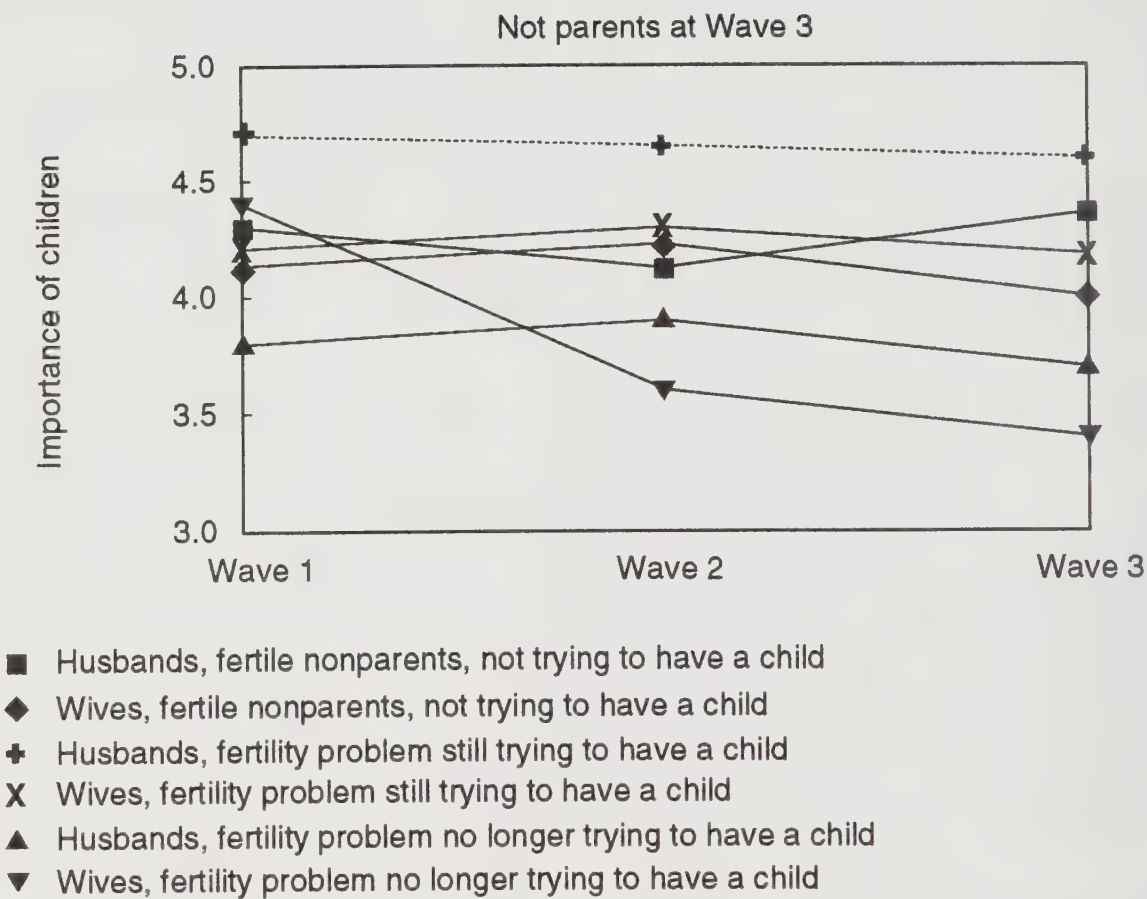


Exhibit 5.9 Confidence in Having a Biological Child* for Married Couples with Primary Infertility in Southeastern Michigan in 1988-1990

Parental status in 1990	Men			Women		
	1988	1989	1990	1988	1989	1990
Live birth	3.6 (61)**	3.2 (5)	NA	3.3 (61)	3.8 (5)	NA
Adoption	2.6 (14)	1.6 (7)	NA	2.5 (14)	1.6 (5)	NA
Pregnant	3.4 (7)	2.5 (8)	NA	3.4 (9)	2.9 (9)	NA
Still trying to have a child	3.4 (84)	2.8 (79)	2.8 (83)	3.2 (85)	2.7 (82)	2.5 (84)
Gave up trying to have a child	2.6 (15)	2.0 (13)	1.6 (13)	2.3 (15)	2.1 (13)	1.4 (12)

* Responses ranged from (1), not at all confident, to (5), extremely confident.

** The number in parentheses represents the number of respondents answering the question.

NA = not applicable

Summary

This initial examination of the trends in the data from our project shows some patterns that are not at all surprising (and that increase our confidence in our subgrouping of the study participants and in their answers to our interview questions) and other patterns that add new and potentially important knowledge about the psychodynamics of infertility.

Among the former results is the finding that the expected final number of children tended to go up for those who became parents or were in couples where the wife was pregnant, down for those who were not parents by the third interview, and sharply down for those who had given up trying to have a biological child. Similarly, confidence in having a biological child declined over the course of the study for members of fertility-problem couples who had not had a child by the third interview, and especially for those who had given up trying for a biological child.

Less obvious is the finding that the importance people attached to having children changed in accord with their actual fertility experience. These data document that those who became parents increased their importance ratings, and those who did not become parents — particularly

those who concluded they could not have their own biological child — decreased the importance they attached to having children. No doubt such attitude changes help people maintain and enhance their mental health and sense of well-being.

Key findings with respect to the psychological indicators are that general stress tended to decrease for those who became parents and for fertility-problem couples who gave up, but not for fertility-problem couples who were still trying. Home life stress, however, tended to increase when a new baby came into the home. Sense of global well-being tended to be stable or increase for those who became pregnant or parents, and also for fertility-problem couples who gave up, but tended to decrease for fertility-problem wives who were still trying at the third interview. Self-esteem did not show marked changes for most groups over the course of the study, but tended to be low for those who adopted a child, and high for members of fertility-problem couples who gave up.

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Review of the Literature on the Psychosocial Implications of Infertility Treatment on Women and Men

Elizabeth Savard Muir



Executive Summary

Written for a semi-professional audience, this report reviews the literature (1975-1991) concerning the psychosocial implications of infertility treatment for women and men. Using the key words "infertility," "treatment," "psychosocial," "male," and "female," documents have been retrieved from the MEDLINE, BIOETHICSLINE, Popline, PsychINFO, Sociological Abstracts, and Dissertation Abstracts data bases. Other sources investigated were the Commission's library holdings, semi-juried collections, and the bibliographies accompanying the Commission's briefs and submissions.

Data bases in three categories (ranks) have been created for all relevant articles and research studies. Case studies and/or surveys or questionnaires dealing with the psychosocial implications of infertility treatments are designated as Rank 1. Articles that are editorial, analytical, prescriptive, or retrospective in presentation are designated as Rank 2. Documents that did not conform to the topic yet are of interest to the subject of infertility are designated as Rank 3.

This report includes reviews of Rank 1 and 2 documents in chart form. Rank 3 articles are identified in the bibliography. The report also incorporates an introduction, summary of findings in Rank 1 and 2

citations, and a conclusion. Two appendices are included: (1) tests used in Rank 1 studies; and (2) mini-analysis of some tests used in Rank 1 studies. The report includes a bibliography containing all documents cited, with an identifying symbol as a Rank 1, 2, or 3 or T (test) document.

Introduction

Constructing a literature review is much like completing a jigsaw puzzle: seeking parts to create a picture. This review began with sorting and identifying relevant studies and articles. The author "turned over many stones" to create a comprehensive review within the time provided. This report documents relevant English and French-language literature concerning psychosocial implications of infertility treatments published in Europe and North America from 1975 to 1991. Its findings suggest guidelines for future uses of various infertility treatments and/or technologies.

The Process

To locate relevant documents, data bases were searched using the key words "infertility," "treatment," "psychosocial," "male," and "female." Medical, social science, and feminist perspectives were represented through searches of the following: MEDLINE, BIOETHICSLINE, Popline, PsychINFO, Sociological Abstracts, and Dissertation Abstracts. Other sources, such as the Commission's library, bibliographies accompanying relevant documents, semi-juried collections, and bibliographies from Commission submissions and briefs, were examined. The main foci of this review were infertility treatment and the psychosocial implications of treatments. There is a large body of literature on "infertility," and this review draws from within this larger subject.

The citations were divided into three categories or "ranks" according to kind and relevance to the topic. Rank 1 studies are case studies and/or surveys or questionnaires. Rank 2 articles are editorial, descriptive, or retrospective in presentation. Rank 3 documents are not specifically on topic, but they relate to the broader subject of infertility.

Data collected and reviewed for Ranks 1 and 2 are summarized according to a standardized format and organized alphabetically within each rank. Descriptions of the headings precede each of these major sections. The data have been retrieved directly from the documents, thereby maintaining objectivity. Reviews of Rank 1 and 2 studies contain available information on tests and samples used. Critical commentary and interpretation were not undertaken. As similar topics are investigated by different researchers and writers, the report may become repetitious at times. This repetition provides useful emphasis. Rank 3 documents are

presented in the bibliography only, without analysis. Summaries of Rank 1 and 2 documents and a conclusion are provided.

In total, the author located, acquired, and reviewed 181 documents: 61 Rank 1 studies, 54 Rank 2 articles, and 66 Rank 3 documents.

The author investigated some Rank 1 tests (see Appendix 1 for a list of tests used in Rank 1 studies). Since few of the source manuals or articles were available through libraries or resource centres and because of time limitations, the author prepared only a mini-analysis of tests from three studies. Information for this analysis was taken from Rank 1 documents, primary source documents, and reference texts and is presented in Appendix 2.

Relevance to the Commission's Mandate

The following statements in *A Guide to the Research and Evaluation Program of the Royal Commission on New Reproductive Technologies* specifically relate to this report's objectives:

Given the numerous gaps in our knowledge and the conflicting interpretations to be clarified, the overriding objective of the Research and Evaluation Program is to ensure that the observations and recommendations made by the Commission in its final report will benefit from and be informed by the most rigorous available research. (p. 6)

In the documentation category, the Commission will bring together data and research findings in the areas of study identified in our mandate to establish baseline information and data — "what is known" — as the necessary foundation for further research. (p. 8)

Other important questions arise from the way infertility is defined. Is it solely a physiological condition? ... What are the social constructions that underlie our definitions of infertility? Does society tend to value women on the basis of their ability to have children ... ? Are there ways other than technology to deal with infertility? ... (p. 11)

An examination of the current status of infertility and of prevention programs in all their broad dimensions will allow the Commission to suggest directions for the future of infertility prevention. In addition, the information gathered will act as a catalyst for future research in this field, because it will offer, for the first time, a comprehensive synthesis of what is known about infertility. (p. 13)

This document, which reviews the literature concerning psychosocial implications of infertility treatment, expresses the author's views and does not necessarily represent those of the Commission.

1. Rank 1 Reviews

Description of Rank 1 Headings

A standardized form was completed for each Rank 1 study. Charts contained in this report specify the author(s), title, source, and year of publication for each article. A summary of each study is provided, with information organized under the following headings:

- **Subject**
Summarizes the study's objectives.
- **Methodology**
Contains a brief description of the research methodology. The standardized tests or instruments used and procedures followed in carrying out the research are specified.
- **Sample**
Contains a brief description of the study sample. In most cases, details are provided regarding the number of participants, how they were selected, and their demographic characteristics.
- **Comments**
Contains information pertaining to the reliability, validity, and bias of the methodology and/or instruments used. Other comments are included as necessary.
- **Conclusions**
Summarizes the study's conclusions.

Space in each field was limited; however, an effort was made to include as much information as possible and to ensure that the summaries reflect the substance of each Rank 1 study reviewed.

Rank 1 Reviews

Andrews, F.M., A. Abbey, and L.J. Halman. 1991. "Life Quality, Psychosocial Factors and Infertility: Some Results from an On-Going Project." Workshop document prepared for the Royal Commission on New Reproductive Technologies, Ottawa, 6 November.

Subject

This document is a handout prepared for a workshop examining research on life quality, psychosocial factors, and infertility.

Methodology

The data were derived from a study carried out in southeast Michigan, involving a series of interviews and questionnaires. Details regarding the instruments used are included.

Sample

The sample comprised 275 white American couples, including 90 fertile couples and 185 infertile couples. Most were middle class and had at least high school education. The mean age of fertile respondents was 31 years for men and 28 years for women. The mean age of infertile respondents was 34 years for men and 32 years for women. Other demographic information is also provided.

Comments

The reliabilities of the major scales constructed for study use are provided in tabular form. Validity and bias reduction not discussed.

Conclusions

The workshop agenda included: psychosocial responses to infertility; couples' behaviours, attitudes, and desires with respect to fertility and infertility; factors linked to infertile couples' subjective well-being; and initial explorations of changes in psychosocial factors associated with changes in parental status. Data analysis was presented in tables and graphs. No summary of findings provided.

Baram, D., et al. 1988. "Psychosocial Adjustment Following Unsuccessful In Vitro Fertilization." *Journal of Psychosomatic Obstetrics and Gynaecology* 9: 181-90.

Subject

The incidence, severity, and length of depression following unsuccessful *in vitro* fertilization (IVF) and the effect of IVF failure on couples' marital and sexual relationships. Couples' reactions at various stages of IVF treatment, how IVF compared to other life stresses, and support systems used to cope with unsuccessful IVF also of interest.

Methodology

Two copies of a randomly numbered questionnaire were mailed to each couple. Husband and wife were instructed to complete it separately and return it anonymously. The questionnaire elicited demographic data, information on the cause of infertility and on marital, psychological, and sexual adjustment following IVF; and coping mechanisms for dealing with unsuccessful IVF.

Sample

The study population included 86 couples who completed at least one IVF treatment cycle and did not become pregnant. Fifty women and forty men (40 couples plus 10 women) returned the questionnaire — a 52 percent response rate. The average time since the last IVF treatment was 1.5 years. Sixty-four percent of couples had attempted IVF once, 18 percent twice, 14 percent three times, 2 percent four times, and 2 percent five times.

Comments

Reliability/validity/bias reduction not discussed.

Conclusions

The effect of IVF failure on couples' marital relationship, sexual functioning, and lifestyle was significant. Sixty-six percent of women and 40 percent of men reported depression following IVF failure; the severity of depression decreased over time. Ninety-four percent of women and 64 percent of men reported somatic and psychological symptoms of depression and anxiety. Of particular concern was the 13 percent incidence of suicidal thoughts among female respondents. In the overall evaluation, however, most couples were pleased with their IVF experiences.

Bell, J.S. 1981. "Psychological Problems Among Patients Attending an Infertility Clinic." *Journal of Psychosomatic Research* 25: 1-3.

Subject

Preliminary description of a pilot study for a proposed longitudinal investigation of the psychological adjustment of couples attending an infertility clinic.

Methodology

Within couples, each partner was assessed separately. Interview and questionnaire data were gathered. A semi-structured interview dealt with demographic details, feelings about infertility, and items thought likely to influence emotional response. It included an assessment of social, sexual, and marital adjustment and a clinical-observer rating of anxiety and depression on four-point scales. Questionnaires included: (a) Sexual Experiences Scales, (b) the Work, Leisure, and Family Life Questionnaire, and (c) the Delusions-Symptoms-States Inventory State of Anxiety and Depression (SAD).

Sample

Twenty couples with a complaint of primary infertility attending the Infertility Clinic of the Royal Infirmary of Edinburgh, 10 attending for the first time (with no previous investigation or treatment) and 10 undergoing

a variety of treatments. The age range for the men was 22-44 years; for the women, 21-38 years. Mean marriage duration was 7 years and mean length of infertility 4.2 years.

Comments

A comparison of questionnaire data and observer ratings showed a correlation of 0.9 between SAD totals and total observer ratings. Validity and bias reduction not discussed.

Conclusions

Complaints of emotional disturbances were common. Interview data also suggested that couples with previously satisfactory sexual relationships may develop secondary dysfunctions as a result of anxieties arising from infertility. Such problems may contribute to infertility. Of the 40 patients interviewed, nine women and four men showed signs of current emotional disturbance, social maladjustment, or secondary sexual dysfunction. In three cases, both partners were affected. Investigations revealed a history of previous psychosocial instability in only two of the women, although both were among the most distressed patients. No other factors of possible predictive value emerged, although this matter was thought to merit further investigation. Findings suggested psychological problems should be considered in infertility management.

Berg, B.J., and J.F. Wilson. 1991. "Psychological Functioning Across Stages of Treatment for Infertility." *Journal of Behavioral Medicine* 14: 11-26.

Subject

The functioning of a cross section of infertile couples in three stages of medical investigation: year 1, year 2, and year 3 and beyond.

Methodology

General psychological functioning was measured using the SCL-90-R test (Derogatis 1977). Marital adjustment was measured using the Locke-Wallace Marital Adjustment Test (MAT). A questionnaire was designed to assess sexual variables. Sexual satisfaction and level of arousal were assessed with five-point Likert scales. Sexual functioning variables were also measured. Couples were categorized according to the amount of time they reported being in contact with medical professionals for infertility treatment. Participants were recruited through RESOLVE (a non-profit organization offering counselling, referral, and support services for infertile couples) and two U.S. medical schools.

Sample

The sample consisted of 104 couples who had tried to conceive for at least 12 months. They heavily represented middle and upper socioeconomic classes. Of these, 85 percent worked in white-collar occupations, 88 percent were college educated, and 53 percent had combined family incomes of \$40 000 or more. The mean age of respondents was 31 years. The couples had pursued infertility treatment for an average of 28 months, with a range of 1 month to 10 years.

Comments

The article noted that the SCL-90-R is reported to have adequate indices of reliability, concurrent/discriminative, and construct validity. MAT also was noted to be reliable. A study limitation was the inability of the cross-sectional design to take account of those couples who discontinued medical investigation.

Conclusions

The data suggest there are significant fluctuations in psychological functioning during the course of medical treatment for infertility. The pattern of scores on the SCL-90-R and indices of marital adjustment and sexual relationship were consistent with a model of infertility-induced strain that includes an acute stress reaction related to diagnosis and the initial phases of treatment, which diminishes over time, overlaid by a chronic strain response that intensifies as treatment continues. Stress experienced during the initial year of treatment affected primarily aspects of psychological functioning. During the second year, psychological indices indicated functioning within a normal range, while levels of sexual arousal were elevated. The third stage (treatment for three years or more) was the most difficult. Psychological strain was comparatively higher and indices of marital and sexual satisfaction were at their lowest levels.

Berger, D.M. 1980. "Couples' Reactions to Male Infertility and Donor Insemination." *American Journal of Psychiatry* 137: 1047-49.

Subject

This study examined conflicts and behaviour patterns in couples after male infertility was identified. It also examined patterns in couples choosing donor insemination (DI). The author believed that the secrecy involved inhibits the resolution of conflicts about infertility and DI.

Methodology

Sixteen couples were interviewed after a diagnosis of azoospermia or severe oligospermia. The interview focussed on these questions: What was each partner's reaction to the diagnosis? Could changes in feeling, thinking,

or behaviour be detected? What conflicts could be inferred from these changes? Was there any pattern to the couple's choosing DI and how did they feel about keeping it a secret? Partners were encouraged to talk freely and questions were interposed to fit the subject at hand. Dream reports were requested from each individual.

Sample

Couples who had been aware of the husband's infertility before marriage, in whom the wife had been found to have a contributing physical pathology, and in whom one of the partners had severe psychopathology were excluded. Sixteen couples were interviewed. The women were 21-34 years old; the men, 21-38 years old. At the time of interview, 10 couples had decided to undertake DI, two had decided against it, and four were undecided.

Comments

Reliability/validity/bias reduction not discussed.

Conclusions

Findings describe a specific, common conflict pattern in couples after a diagnosis of male infertility: impotence, depressive mood and/or depressive equivalents in the husband, and hostility and guilt in the wife. In only two of 16 couples did neither partner reveal signs or symptoms that would provide evidence for this pattern. Of the 10 couples who decided to try DI, six had delayed 21 months to four years and were better adjusted than three of the four couples who did not. The decision involves two problem-solving stages: (1) coming to terms with the infertility; and (2) confronting the problems of DI. The secrecy that surrounds DI may interfere with successful progression through this two-stage process. The implication for clinical management is that serious discussion relating to DI might best be postponed for three to four months after completion of infertility work-up.

Berger, D.M., et al. 1986. "Psychological Patterns in Donor Insemination Couples." *Canadian Journal of Psychiatry* 31: 818-23.

Subject

The study demonstrates that couples undertaking DI experience conflict from two sources: the discovery of infertility and the undertaking of DI. It also attempts to demonstrate that the conflict originating in infertility should be acknowledged, discussed, and to some extent resolved before the couple undertakes DI and confronts the conflicts evoked by the procedure. Further, the secrecy that surrounds DI may contribute to the

denial and non-resolution of conflict. A brief survey of literature dealing with the psychological impact of DI is provided.

Methodology

Over a 13-year period, DI applicant couples were encouraged to consult an attending psychiatrist. Couples who had successfully undertaken DI and those who decided against it were seen in follow-up interviews. Some couples were specifically asked to report patterns of sexual behaviour, dreams, length of interim period between the identification of infertility and the decision to undertake DI, and their course during DI. The discussion of the role of secrecy is supplemented by the findings of a questionnaire applied to another sample group.

Sample

One hundred and twenty couples were interviewed. Most were in consultation only once. Six couples requested and received brief psychotherapy (no more than 12 sessions) at various stages of infertility work-up and treatment. The questionnaire on secrecy was completed by 76 couples who were about to undertake DI or had successfully undertaken it (as well as 76 others). These couples had not been seen in psychiatric consultation. Sixteen couples reported on patterns of sexual behaviour, dreams, etc.

Comments

Reliability/validity/bias reduction not discussed.

Conclusions

The clinical findings provide evidence that the discovery of infertility generates transient impotence, loss of self-esteem, and withdrawal in husbands and anger, guilt, and a wish to make reparations in wives. The DI procedure itself evokes oedipal conflicts. Couples should recognize, discuss, and come to terms with the conflicts generated by the discovery of infertility before tackling DI. Although secrecy is advocated by most DI couples and physicians, the questionnaire results disclosed that in 58 percent of couples at least one partner considered it psychologically useful to discuss their infertility with others. Secrecy may be useful, but it may also, through the indirect sanction of denial and negation, interfere with the couple's acknowledgement and discussion of their problems.

Bernt, W.D., et al. 1989. "The Role of Anxiety as a Psychological Co-Factor in Invasive Treatment of Sterility." *Zentralblatt für Gynäkologie* 111: 1220-23.

Subject

The role of anxiety as a co-factor in sterility management. The importance of anxiety as a disturbing factor during invasive sterility therapy is demonstrated.

Methodology

No details available.

Sample

Eighty-seven women of an IVF and gamete intrafallopian transfer series were investigated using a standardized anxiety inventory.

Comments

In German. English abstract and references on file.

Conclusions

Not available.

Bresnick, E.R. 1981. "A Holistic Approach to the Treatment of the Crisis of Infertility." *Journal of Marital and Family Therapy* 7: 181-88.

Subject

The importance of assessing the impact of infertility on couples/individuals and understanding the relevance of the impact in context of psychological treatment. Three psychological-behavioural categories, based on several years' work with infertile couples/individuals, are proposed. Detailed case studies in each category are presented to illustrate the impact of the infertility crisis and the role of psychological intervention.

Methodology

Couples/individuals received psychotherapeutic referrals in conjunction with a total medical work-up; they were offered three options: (1) short-term group work, (2) private treatment along with spouse, or (3) private treatment individually. Their infertility crises were measured by assessing factors including spousal communication, mutual investment in problem solving, and creativity. (There were 14 areas of assessment.) An attempt was made to differentiate between the quality of marriage before and following the recognition of infertility.

Sample

Sixty-three couples/individuals who accepted a psychotherapeutic referral while seeking infertility treatment. Number of people referred unknown. Three detailed case studies included.

Comments

Because of numerous uncontrolled variables in the referral process and subsequent acceptance of the referral, the patients' psychopathology or general psychological status probably is skewed. Reliability and validity not discussed.

Conclusions

Infertility tends to arouse, perpetuate, and exacerbate psychological and emotional turmoil that can be successfully treated by therapeutic intervention regardless of the diagnosis and outcome of the infertile condition. Expanded awareness of available medical tests, and the reasons for them, as well as evaluation of their results and subsequent treatment can minimize patients' feelings of helplessness and loss of control. Education about the medical aspects of infertility provides a basis for communication and involvement between partners. The therapist can use this pattern of communication to help clients investigate the deeper emotional impact of the crisis and help them to grieve the loss of their fertility. Successful therapeutic treatment should result in the resolution of the infertility crisis.

Bresnick, E.R., and M.L. Taymor. 1979. "The Role of Counseling in Infertility." *Fertility and Sterility* 32: 154-56.

Subject

This preliminary report attempts to bring objective evidence to bear on the effectiveness of counselling in terms of the amelioration of emotional symptoms secondary to the state of infertility.

Methodology

Couples undergoing infertility treatment were offered counselling and those that accepted the referral were seen for short- or long-term treatment. To evaluate the presence of emotional symptoms before and after treatment, as well as the effectiveness of counselling, a questionnaire was sent to each patient. Responses to two questions were evaluated. In the first, individuals were asked to grade (1-5) their feelings of guilt, anger, frustration, and isolation. In the second, patients evaluated several problem areas, such as sexual adjustment and career attitude.

Sample

Initially 212 infertile couples were offered counselling and 62 accepted the referral. Forty-six individuals or couples were seen for short-term treatment and 16 for long-term treatment. A total of 111 individuals (13 women and 49 couples) were asked to complete questionnaires. Fifty-six were returned. No demographic information provided.

Comments

Reliability/validity/bias reduction not discussed.

Conclusions

Before counselling, the emotional symptomatology reported by female partners was more intense than that of the males. In terms of problem areas, differences between men and women were not as distinct. Women had most difficulty with attitudes toward ultimate failure of infertility treatment, while men had more difficulty in the area of communication. Women's initial symptoms of guilt, anger, frustration, and isolation decreased after counselling, and long-term counselling had more impact than short-term. There appeared to be a lesser degree of improvement in terms of men's emotional symptomatology. With regard to problem areas, short-term counselling was of little help, although long-term counselling had positive impacts for men in all areas. Infertility counselling, combined with medical diagnosis and treatment, can enhance the quality of life of many victims of the "infertility crisis."

Burns, L.H. 1990. "An Exploratory Study of Perceptions of Parenting After Infertility." *Family Systems Medicine* 8: 177-89.

Subject

The long-term effects of infertility on the psychosocial functioning of families. Also, perceptions of parenting in 20 infertility-treated families and in 10 families with no history of reproductive failure.

Methodology

Two groups of parents, those treated for infertility and those with no experience of reproductive problems, were compared in terms of their perceptions of parenting. Semi-structured interviews and paper-and-pencil measures were used. The latter consisted of 26 measures designed to discriminate overprotective/child-focussed parenting and abusive/neglectful parenting. The items adapted were: the Parental Opinion Form; the Predictive Questionnaire; the Child Abuse Potential Questionnaire; and a description of child-centred families.

Sample

The infertility-treated sample was taken from a list of patients with the "endocrinology/infertility" diagnosis code at the University of Minnesota Hospitals in 1971-1976. Of 250 women who qualified, only 20 could be reached, had become parents, and were willing to be interviewed. None had become parents as a result of IVF or DI. Six husbands were also interviewed. The comparison group was made up of 10 women and three husbands referred by the subjects.

Comments

A major limitation was the small sample. Dissatisfaction with the instruments also was discussed. Chi-square analysis of interview data showed strong inter-rater reliability.

Conclusions

Most subjects (85 percent) rated infertility as a negative experience that had caused varying degrees of disruption and alteration in their lives. Men seemed to find this disruption less severe than women. Seventy-six percent of subjects reported that infertility had caused conflict in their marriages; this was significantly higher than the incidence of marital problems reported by the control group. Of respondents who had experienced infertility, 57 percent believed that becoming parents made them closer; fewer than 30 percent of the control group expressed this sentiment. Subjects with a history of infertility reported far more problems in themselves, their marriage, their parenting, and their children. Half of them reported varying degrees of difficulty in bonding or problems with entitlement. Physicians and other professionals must take greater responsibility in helping couples define the realistic parameters of their medical treatment.

Callan, V.J., and J.F. Hennessey. 1988. "Emotional Aspects and Support in In Vitro Fertilization and Embryo Transfer Programs." *Journal of In Vitro Fertilization and Embryo Transfer* 5: 290-95.

Subject

Women's perceptions of the emotional demands of IVF and embryo transfer (ET) with explanations for failed attempts, and their coping strategies and sources of emotional support.

Methodology

Women currently involved in an IVF program (all had completed at least one attempt) were asked to complete a questionnaire about their IVF experiences. It consisted of both open-ended questions and rating scales. Open-ended questions dealt with factors women believed prevented them

from becoming pregnant through IVF, parts of the procedure difficult for them, and their personal coping strategies. Responses were coded and analyzed. Six-point Likert scales rated the support received from others and optimism at each IVF attempt. A two-hour, semi-structured interview followed.

Sample

Seventy-seven infertile women involved in the same IVF-ET program. On average, they were 32 years old and their husbands were 36 years old. They were married nine years and had known of a fertility problem for six years. The majority had high school education with some additional technical training and 12 percent had some college qualifications. About half worked outside the home. The demographic characteristics of the women matched those reported in other studies.

Comments

The coding of responses to open-ended questions was found to have an intercoder reliability of 0.80 to 0.95. Validity and bias reduction not discussed.

Conclusions

Women tended to be too optimistic in their initial attempts at IVF, but optimism generally declined with each attempt. They experienced considerable stress over several stages, in particular during the work-up before hospitalization and the wait after the procedure. Women possibly need the highest level of emotional support when they are not directly involved in the procedure; that is, as they wait at home. Counselling and support are critical if the attempt fails. Women attribute their lack of success to both medical and psychological components and seem to employ many normal coping strategies. Most women believed that although they would be less fulfilled if they did not have a child through IVF-ET, there were alternative sources of satisfaction to pursue.

Callan, V.J., et al. 1988. "Toward Understanding Women's Decisions to Continue or Stop In Vitro Fertilization: The Role of Social, Psychological, and Background Factors." *Journal of In Vitro Fertilization and Embryo Transfer* 5: 363-69.

Subject

To predict and understand women's intentions about continuing or discontinuing IVF through examining the roles of internal or psychological variables, in particular patients' beliefs about IVF and the role of social pressures and patients' background.

Methodology

Women currently in an IVF-ET program and who had at least one treatment cycle were mailed a structured questionnaire. Initial questions gathered demographic information and specific information about involvement in IVF-ET. Much of the questionnaire measured components of Ajzen and Fishbein's theory of reasoned action. A multivariate analysis of variance (ANOVA) was conducted on the responses to 12 measures to determine differences in background between women continuing and discontinuing IVF. The predictive usefulness of personal and social influences was determined using regression analysis.

Sample

A group of 423 women were contacted and asked to complete questionnaires. Of those questionnaires, 254 were returned — about 60 percent. Of these, 182 wanted to undergo another treatment cycle in the next year. The continuers were on average 33 years old and their husbands were 35; 65 percent had completed high school and 31 percent were college/university educated. The 72 discontinuers were on average 34 years old and their husbands 37 years old; 75 percent had high school education and 21 percent were college/university educated.

Comments

The author noted substantial evidence to support the assumptions and relationships described in the Ajzen and Fishbein theory. The questionnaire thus has a strong theoretical base. Bias reduction and reliability not discussed.

Conclusions

Women not intending to continue IVF had older husbands, a large proportion were mothers, and more of them had had an IVF pregnancy. Those stopping and continuing did not, however, differ in terms of their ages, the length of their infertility, or their number of IVF attempts. Women's intentions with respect to IVF were best predicted by their attitudes toward another attempt and their perceptions of social pressures. Discontinuers were less optimistic about another attempt making them mothers, making their marriages happier, or improving the quality of their lives. Both groups judged another IVF attempt as likely to involve some stress, disappointment, and financial strain. Although not highly compliant, continuers were more willing to comply with the wishes of family members, close friends, other infertile women, parents, and their doctor in the IVF program. Most couples seemed to be emotionally well-adjusted and able to deal well with stress.

Chan, Y.F., et al. 1989. "Psychosocial Evaluation in an IVF/GIFT Program in Hong Kong." *Journal of Reproductive and Infant Psychology* 7: 67-77.

Subject

Psychosocial evaluation of 112 couples consecutively enrolled in an IVF/gamete intrafallopian transfer (GIFT) program in Hong Kong. The study presents the couples' perceptions of their infertility and of IVF/GIFT procedures at the initial evaluation. It was hoped that the study would provide a baseline for a prospective study of the couples' emotional response during and after treatment and would identify couples at risk of developing psychological disturbance during treatment so that psychosocial support and counselling could be provided.

Methodology

Couples were evaluated by one of three investigators in semi-structured pre-treatment interviews focussing on information regarding IVF/GIFT procedures and success rates, attitudes toward infertility, attitudes toward IVF/GIFT, social support available to the couples, and future plans if pregnancy did not occur. Subjects were asked to complete the following: (a) Eysenck Personality Questionnaire; (b) State-Trait Anxiety Inventory (STAI); (c) Leeds Scale (Snaith et al. 1976); and (d) General Health Questionnaire (GHQ) (30-item version). Only the first two questionnaires were answered by all subjects.

Sample

The sample consisted of 112 couples consecutively enrolled in the IVF/GIFT program. Most had a long history of infertility (mean of 6.09 years) and some had been seeking treatment for up to 12 years (mean of 4.55 years). The women had a mean age of 33.3 years; the men, 36.4 years. Of these, 57.1 percent of women and 52.7 percent of men had secondary education, and 12.5 percent of women and 19.6 percent of men had graduate education. Almost all the subjects were Chinese.

Comments

Reliability/validity/bias reduction not discussed.

Conclusions

The couples scored well below the psychiatrically "at risk" point on the GHQ. Given that most had long histories of infertility treatment, it may be that they were well-equipped to deal with disappointment. The women showed significantly higher scores on anxiety measures than their spouses. More than 70 percent of couples could accurately recall the success rate quoted to them during their first clinical interviews. They recalled procedural details much better than possible complications arising from

them; however, there was no correlation between the amount recalled and personality variables or pre-treatment psychological status. Eighty percent considered the treatment their last resort, and one-third regarded adoption as an alternative. Only half the women and even fewer men had social support systems. It was expected that the couples would undergo significant emotional strain when they began treatment.

Clark, A., et al. 1987. "Social and Reproductive Characteristics of the First 100 Couples Treated by In Vitro Fertilisation Programme at National Women's Hospital, Auckland." *New Zealand Medical Journal* 100: 380-82.

Subject

Basic social and demographic data for patients treated at National Women's Hospital, Auckland, New Zealand, by IVF.

Methodology

Reproductive and social histories were taken of the first 100 couples treated in the IVF program. Data also available from another 159 couples awaiting IVF treatment in July 1985.

Sample

Only couples with infertility resulting from irreparable tubal damage were accepted for treatment. The sample consisted of 100 couples in long-standing, stable relationships, with not more than one child from their current marriage. All received counselling from a social worker before being accepted into the program. The upper age limit for the women was 40. The men were required to have adequate semen quality.

Comments

Reliability/validity/bias reduction not discussed. Intended to provide baseline data.

Conclusions

The first 100 couples treated with IVF were of higher socioeconomic status and contained a lower proportion of non-Europeans than the general population. One-half of them were accepted during the first six months of the program's operation before its existence was widely known. These couples were highly motivated and members of a local infertility society. Statistics from the next 159 couples awaiting treatment indicate these biases are diminishing and IVF is becoming more accessible. During the first two years of the program, only nine of the 100 couples withdrew before they became pregnant or had received their quota of treatment cycles. One woman died, one couple separated, and seven found aspects of IVF too

stressful to continue. Further detailed group demographic data are presented and discussed.

Czyba, J.-C., and M. Chevret. 1979. "Psychological Reactions of Couples to Artificial Insemination with Donor Sperm." *International Journal of Fertility* 24: 240-45.

Subject

The study attempted to answer these questions: How did the couple choose DI? What were the motivations of the man and woman? How did couples experience the pregnancy and the birth? How does DI influence relationships within the couple? Is the baby considered to be the mother's alone? Should DI be given to any couple requesting it?

Methodology

After initially contacting the couples by letter, 90-minute interviews were undertaken. Most took place in the participants' homes during pregnancy or after childbirth. Interviews were non-directive in form. Later interviews consisted of a non-directed discussion, followed by a systematic exploration of certain themes or sociological conditions. After quantitative analysis of spontaneously discussed topics, an effort was made to reconstruct the couples' life histories and experiences.

Sample

Sixty-two couples whose insemination resulted in pregnancy. Over the same period, 433 requested DI, 273 couples were inseminated and 90 successful inseminations resulted. Participants' sociological background varied but most were of middle-class origin. The women were 25-36 years old and the men were 26-45 years old. Most professed to hold religious beliefs. Couples were not obligated to participate in the study.

Comments

Reliability/validity/bias reduction not discussed.

Conclusions

Couples' case histories were surprisingly similar. Several distinct stages were observed: awareness of wanting a child while the woman cannot become pregnant; the investigation of sterility and discovery that the husband is sterile; a period of adaptation; the disappearance of guilt feelings in the husband and wife; acceptance of the idea of DI; request for DI; conflict with the medical profession; disturbing DI sessions, usually in the presence of the husband; uneasiness at the beginning of pregnancy; euphoric continuation of pregnancy; uncomplicated delivery of a child whose father is involved in its upbringing; then, the request for a second child by DI.

Daniels, K.R. 1989. "Psychosocial Factors for Couples Awaiting In Vitro Fertilization." *Social Work in Health Care* 14 (2): 81-98.

Subject

Literature review on the psychological and psychosocial aspects of IVF and consumer attitudes toward IVF. Presents the results of a questionnaire completed by couples awaiting IVF treatment in Auckland, New Zealand. Data were intended to provide a baseline for follow-up research and a consumer perspective on developments in the field of artificial reproduction.

Methodology

The questionnaire (available from the author) consisted of 54 questions and included both Likert-type and open-ended questions. Subjects dealt with in the questionnaire: demographic characteristics; responses to infertility; decision making regarding infertility and IVF, both present and future; and policy and ethical issues. The Locke-Wallis Marital Interaction Test also was used, but its results were to be reported in a separate paper.

Sample

The population sample comprised 101 couples on the waiting list for IVF at National Women's Hospital, Auckland, New Zealand. Of these, 79 couples agreed to participate in the study and were mailed questionnaires; 61 couples completed and returned the questionnaires. Respondents' average age was 31 years old, and 41 percent were in professional, technical, administrative, or managerial occupations. Further, 26 percent had three years or less university education; 12 percent had university qualifications.

Comments

The research objective was to obtain a consumer perspective on the experiences that led couples to seek IVF, reactions to infertility, issues and problems, expectations of treatment, and attitudes toward moral and ethical issues involved. Reliability/validity/bias reduction not discussed. Contains an overview of research in this field.

Conclusions

In general, there was an apparently equal commitment to IVF by women and men, but few women stated they were more influential in the final decision to try IVF. More women than men stated that attitudes and responses toward their partner had changed. The results highlight a need for more support and discussion about infertility and IVF. In relation to IVF, couples clearly wished to have a social worker or counsellor available throughout the process. Support groups play an important role in providing comprehensive service, especially as secrecy was not reported to be a major issues for most couples. Respondents seemed not really aware of the emotional treadmill they would likely experience while undergoing

IVF. As reported in other studies, couples undergoing IVF overestimated the success rate.

Daniluk, J.C. 1988. "Infertility: Intrapersonal and Interpersonal Impact." *Fertility and Sterility* 49: 982-90.

Subject

To determine if changes occur in the marital relationships, sexual satisfaction, and levels of psychologic distress of couples as they progress through the medical investigation of their infertility.

Methodology

Six questionnaires were administered independently to couple members immediately after the initial visit, four weeks later during medical testing, within one week of diagnosis, and six weeks after diagnosis. The following tests were used: (1) SCL-90-R; (2) Relationship Change Scale; (3) MAT; and (4) Index of Sexual Satisfaction. An experimenter-generated questionnaire elicited information on the subjects' views of the need for, nature of, and timing of psychologic intervention in the area of infertility. Primary data analysis was conducted using the BMDP computer program 4V statistical software.

Sample

A sample of 63 couples attending an infertility clinic. Both partners had to give their consent. None had received a previous diagnosis for their fertility concerns, had parenting experience, had a history of psychiatric diagnosis or treatment, or consumed mood-altering drugs. Twelve voluntarily withdrew during the study and seven were dropped because of prolonged problems with diagnosis.

Comments

The reliability, validity, and internal consistency of the various instruments have previously been demonstrated. Detailed discussion is included.

Conclusions

Medical infertility investigation, and the intrusive procedures involved, were not in themselves influential in altering the levels of sexual satisfaction reported by participants; however, some couples were experiencing dissatisfaction since before the intervention. For most, investigation did not coincide with positive or negative changes in their levels of marital adjustment. In fact, it appeared to enhance the quality of the couples' relationships. Participants experienced significantly more stress at the initial medical interview, with stress subsiding as the investigation proceeded. The receipt of positive, negative, or neutral diagnostic information did not appear to be a factor in inducing stress; for

the women, the receipt of diagnostic information seemed to induce more stress. Most participants felt a need for psychological services.

Demyttenaere, K., et al. 1988. "Anxiety and Conception Rates in Donor Insemination." *Journal of Psychosomatic Obstetrics and Gynaecology* 8: 175-81.

Subject

The relationship between state anxiety and the probability of conception among women entering a DI treatment program.

Methodology

All women entering a DI program from September 1984 to May 1985 were prospectively evaluated using a Dutch translation of the Spielberger Trait Anxiety Inventory. The test was administered by the same psychiatrist immediately before the first DI. During the research period, women who conceived were divided into seven pregnancy groups (i.e., pregnant during first through seventh treatment cycles). Test results were statistically analyzed and compared.

Sample

A total of 116 women were evaluated initially. All couples were married and had no manifest psychiatric disease. The mean age of the men was 32 years; of the women, 30 years. The mean duration of infertility was 5.5 years. Of the 116, 29 couples already had one or two DI children. Sixty women conceived. The age of the women, duration of infertility, and gynaecological and andrological data were comparable for all groups.

Comments

The test-retest reliability of the Dutch Spielberger test was 0.75 to 0.92; its validity was assessed by comparing its results with the results of psychometric tests, clinical judgments, and psychophysiological research. Bias reduction not discussed.

Conclusions

A statistically significant relationship was found between initial trait anxiety levels and the number of treatment cycles necessary for conception. In addition, women having early spontaneous abortions were initially more stressed than others who became pregnant. No significant correlation was found between duration of infertility and trait anxiety. This argued against the current view that women suffer from psychological problems as a result of the duration of infertility investigations and treatment. Other clinical experience, however, suggests a relationship between long duration of infertility and neurotic anxiety.

de Zoeten, M.J., T. Tymstra, and A.T. Alberda. 1987. "The Waiting-List for IVF. The Motivations and Expectations of Women Waiting for IVF Treatment." *Human Reproduction* 2: 623-26.

Subject

Women on the IVF waiting list at the Dijkzigt Hospital in Rotterdam, Netherlands, were surveyed to gain an insight into their motivations and expectations.

Methodology

A questionnaire was sent to a random sample of women on the waiting list for IVF treatment at the beginning of 1986.

Sample

The questionnaire was sent to 129 women. Six questionnaires were returned, and three more women already had become pregnant. Eighty-eight of the remaining 120 questionnaires were processed — five of these were unusable. The mean age of the sample was 32 years. Nearly all women were married. The mean age of their partners was 35 years. More than 25 percent already had children, 19 percent had already undergone IVF, and 95 percent had been treated for infertility.

Comments

Detailed reporting of questionnaire responses included. Sample too small for analysis of differences between subgroups. Validity/reliability/bias reduction not discussed.

Conclusions

Respondents were not well informed about the various aspects of the IVF procedure and were too optimistic about its chances of success. Even if the chances of success were low, most women would choose to undergo IVF. The existence of IVF presents infertile women with a new, difficult choice: undergoing treatment involves costs, but women might regret a decision not to undergo IVF. Respondents said that anticipation of feelings of regret was one of their main motives for undergoing IVF. This "anticipated decision regret" gives IVF a strongly compelling character. Few women said that they needed social guidance in their decision making.

Donnell, C.J.S. 1990. "Representation of Illness in the Prediction of Psychological Adjustment Among Infertility Patients." Ph.D. dissertation, George Washington University.

Subject

A health model of reactions to stress (illness) and investigation of the processes involved in concurrent emotional adjustment for patients experiencing the stressor of infertility and its treatment.

Methodology

Subjects completed questionnaires provided during their initial visit to a private clinic. These included: a biographical data questionnaire; Health and Daily Living Form Manual (coping index); Rotter Internal Versus External Control of Reinforcement; Illness Effects Questionnaire; Beck Depression Inventory; STAI; and Dyadic Adjustment Scale (satisfaction subscale). The biographical data questionnaire also contained three self-efficacy questions. Statistical methods were employed to analyze the data.

Sample

Newly referred patients were selected from three private practices. Subjects were women aged 24-42 years. The number of pregnancies was zero to five per patient; the number of months infertile was up to 96. The women had typically been seen previously by other physicians for infertility. About 127 questionnaires were distributed; 46 were completed by women and seven by men. Reported data are based from female participants only.

Comments

The reliability and validity of the instruments used was reported to be high. Detailed discussion included study limitations, including the possibility of bias based on self-selection and a lack of baseline data.

Conclusions

The results supported a dynamic self-regulation process model in the development and effect of a patient's representation of her medical condition. It appeared that the use of avoidance coping style has a significant role in the individual's development of representation or perception of illness. Perception of illness coupled with the patient's perception of her own ability to control her treatment and eventual outcome accounted for 70.3 percent of the variation in depression. In addition, a high proportion of variation in anxiety (46.4 percent) was explained by perception of illness alone. Perception of illness did not assume a critical role in marital satisfaction, but it emerged as a significant variable with other relevant factors. Understanding the patient's perception or representation of illness is critical in explaining the degree to which patients experience depression or anxiety.

Downey, J., et al. 1989. "Mood Disorders, Psychiatric Symptoms, and Distress in Women Presenting for Infertility Evaluation." *Fertility and Sterility* 52: 425-32.

Subject

Depression in women undergoing infertility treatment to distinguish between subjective distress, symptoms, and clinical depressive disorders.

Methodology

Baseline questionnaire included five assessment areas: reproductive history and psychological response to it, partner relationship, sexual functioning, self-esteem, and psychopathology. Questionnaires used: (1) Reproductive Functioning Questionnaire (developed by investigators); (2) Partner Relationship Satisfaction Scale (adapted from the Marital Pre-Counselling Inventory); (3) Sexual Behaviour Scale (adapted from PERI (Psychiatric Epidemiology Research Interview)); (4) Self-Concept Scale (adapted from PERI); (5a) Brief Symptom Inventory (abbreviated form of SCL-90-R); and (5b) Mood Disorder Questionnaire (adapted from the Schedule for Affective Disorders and Schizophrenia — Life-Time Version (SADS-L)).

Sample

In the initial assessment of a prospective, longitudinal study, 59 women presenting for infertility treatment were compared with 35 women presenting for routine gynaecological care. The sample was derived from 740 women who completed the initial screening questionnaire.

Comments

First analysis of a four-year longitudinal study. No evidence of validity/reliability testing presented; however, the demographic background of the study group (subjects and controls) is detailed. Also discussed are the scales and questionnaires (including validity and bias) used to compose the baseline questionnaire.

Conclusions

Infertility patients and controls were not significantly different on self-reported measures of partner satisfaction, sexual functioning, or self-esteem. Also, no difference in psychiatric symptomatology, or in the percentage of subjects who were experiencing or had ever experienced major depression. However, the infertility patients perceived themselves to have been already affected by their inability to conceive (e.g., 49 percent reported changes in their sexual functioning and 74.6 percent reported mood changes).

Drake, T.S., and G.M. Grunert. 1979. "A Cyclic Pattern of Sexual Dysfunction in the Infertility Investigation." *Fertility and Sterility* 32: 542-45.

Subject

To determine the incidence of sexual dysfunction at the time of post-coital testing and to characterize the dysfunction pattern in affected individuals. The paper also briefly considers the possible contribution of treatment to sexual dysfunction.

Methodology

Forty-five percent of the couples had a two-hour post-coital test (PCT) and the remaining had overnight PCTs. Statistical analysis ensured that the test method did not influence results. Couples with negative or equivocal results were scheduled for a second test a month later. Couples with repeat negative results were carefully interviewed concerning possible sexual dysfunction.

Sample

Fifty-one infertile couples. All gave normal sexual histories and had been infertile for at least one year. Eleven percent had negative or equivocal results after the first PCT. After the second test, four were found normal, one couple failed to keep the appointment, and six had repeat negatives. These six were then interviewed.

Comments

Statistical analysis of test results indicated no bias on the basis of test method. Reliability/validity not discussed.

Conclusions

One major psychological abnormality that can contribute to infertility is male sexual dysfunction. Five (10 percent) of the couples scheduled for routine PCTs demonstrated some mid-cycle sexual dysfunction. By current standards, these couples did not meet strict criteria for clinically significant sexual dysfunction since it occurred less than 25 percent of the time. The most important observation was the mid-cycle pattern of sexual dysfunction present in all five couples. Factors contributing to this were: (1) the "this is the night" syndrome; (2) a change in purpose of sexual intercourse; (3) the stress of clinical testing by third party; and (4) self-doubt regarding adequate future performance. The infertility work-up may increase the impact of the "this is the night" syndrome. Management of these couples involved discontinuation of testing for six months, reassurance that such dysfunction is normal, and counselling.

Fagan, P.J., et al. 1986. "Sexual Functioning and Psychologic Evaluation of In Vitro Fertilization Couples." *Fertility and Sterility* 46: 668-72.

Subject

The incidence of sexual dysfunction among IVF patients, assessing sexual functioning using psychometric measures and clinical impressions to gather preliminary descriptive data. In addition, the couples' psychological status was evaluated.

Methodology

Couples were requested to have a psychological assessment as part of standard IVF protocol. They were interviewed together regarding their reaction to infertility and their expectations of IVF. The evaluator then saw each spouse separately; a complete psychosocial and sexual history was taken and a mental status examination performed. Each subject completed the Derogatis Sexual Functioning Inventory. The *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III) provided criteria for each diagnostic category. Psychometric data were used to corroborate clinical diagnosis.

Sample

Forty-five of the first 49 married couples accepted to the IVF program during 1984. The mean age of the men was 36.8 years; of the women, 33.8 years. The subjects came exclusively from the professional, upper middle, and middle socioeconomic classes. The mean duration of attempting a successful pregnancy was 5.8 years.

Comments

Reliability/validity/bias reduction not discussed.

Conclusions

In total, 19 sampled individuals had a sexual dysfunction or a psychological disorder. Couples with a sexual dysfunction were more likely to have unexplained infertility. The Brief Symptom Inventory of the Derogatis Sexual Functioning Inventory provided group scores within the normal range for women and men. There did not appear to be a basis for concluding that IVF participants have any higher estimated incidence of sexual dysfunction and psychiatric disorders than the general population. The data support the inclusion of psychological assessment of couples as a standard consultation procedure within the IVF protocol.

Ferber, G.M. 1989. "The Psychological Effects of Previous Infertility on a Pregnancy." Ph.D. dissertation, Boston College.

Subject

The effects of previous infertility and three different infertility treatments on women in the first trimester of pregnancy.

Methodology

Subjects were divided into hormonal, surgical, and IVF/GIFT treatment groups. The control group consisted of women with normal pregnancy experiences. Near the end of the first trimester, all women completed the STAI and the Maternal Adjustment and Maternal Attitudes to Pregnancy Instrument. The latter was broken into subscales of body image, sexual attitudes, marital relationships, somatic symptoms, and attitudes toward the baby and pregnancy.

Sample

A total of 84 pregnant, married, and nulliparous women participated, 29 in the hormonal, 20 in the surgical, and 11 in the IVF/GIFT group. The control group consisted of 24 women. The groups were well-matched in terms of mean length of pregnancy. The previously infertile women were 24-40 years old and the control subjects were 25-36 years old. Women in the IVF/GIFT group were of lower socioeconomic status than expected. Other demographic information provided.

Comments

Validity and reliability of the instruments discussed in detail. The possibility of biased results as a result of sample characteristics and the way in which the sample was obtained was also discussed.

Conclusions

The study did not find that pregnant women who had experienced infertility were more anxious or had more difficulty in adjusting to their pregnancies than women in the control group. No differences were found among women who had experienced different kinds of infertility. The study indicated that women who had conceived after infertility had a better attitude toward the pregnancy and their baby. It is possible that previously infertile subjects were more anxious and more distressed before they conceived and that their anxiety and distress then lessened. The results may also imply a "honeymoon" period, or the benign answers in the study may mask underlying emotions that the participants deny or avoid. It was noted that the pertinent literature is marred by an over-reliance on speculative and clinical data with little use of formal measurements and empirical techniques.

Frank, D.I. 1990a. "Factors Related to Decisions About Infertility Treatment." *Journal of Obstetric, Gynecologic, and Neonatal Nursing* 19: 162-67.

Subject

Preferences held by 147 infertile people about treatment options and the factors perceived as most important in making decisions about undergoing treatments.

Methodology

Participants completed a three-part questionnaire. The first part elicited general information about subjects' biographical and medical characteristics. The second part asked them to rank a list of infertility treatment options according to their acceptability. The third part focussed on identifying factors that might or did influence the subjects' decisions about undergoing various treatments.

Sample

The sample consisted of 37 subjects who responded to an article published in the national RESOLVE newsletter and 212 members of seven RESOLVE chapters. Of the 249 questionnaires disseminated, 147 were returned with usable data. Those who returned usable questionnaires were 40 men and 17 women. Their average age was 31.5 years; their modal income was \$20 000 to 30 000 a year. Eighty percent had been in infertility treatment for at least three years.

Comments

The findings are limited in generalizability by the nature of the sample. Although the subjects' demographic characteristics are not dramatically different from those found in other infertility research studies, their membership in RESOLVE may have provided discussion opportunities, etc., that biased the results. Reliability and validity not discussed.

Conclusions

Results suggest that patients prefer infertility treatment options of a more routine, less intrusive, and non-controversial nature. Medical regimens, artificial insemination (AI) with husband's sperm, and surgical procedures were ranked high. Personal and partner's beliefs were important factors when considering treatment options. The physician's advice and, specifically, the probability of treatment effectiveness were also considered important. Emotional stress was a common theme in the decision process, receiving an overall ranking of four in importance and appearing in the top three for several specific treatment options, including adoption and childlessness. The significance of emotional stress seemed to be particularly elevated early in infertility treatment and for clients who

had been involved in treatment for longer-than-average periods. Legal factors were important, but only for those treatments where legal aspects predominated.

Frank, D.I. 1990b. "Gender Differences in Decision Making About Infertility Treatment." *Applied Nursing Research* 3: 56-62.

Subject

To determine gender differences in decision making about infertility treatment.

Methodology

Participants were members of RESOLVE chapters. Participation was voluntary and anonymous. A questionnaire was designed by the researcher in collaboration with two physicians specializing in infertility treatment. General biographical and medical information was elicited, and participants were asked to identify and rank factors that could influence or had influenced their decisions about undergoing seven categories of infertility treatment. Factors were identified on the basis of a comprehensive literature review. Results were analyzed using an assigned point system.

Sample

The sample consisted of 40 men and 107 women. The average age of subjects was 31.5 years and 94 percent were white. Of these, 84 percent had some college education. Eighty percent had been in treatment for at least three years.

Comments

The questionnaire was pilot tested by couples in infertility treatment who were known to the researcher. It was judged to be inclusive, as well as allowing for additional factors to be identified in an open-ended comment section. Bias may have resulted in that all subjects were members of RESOLVE and that subjects were required to impose an order of importance on decision factors.

Conclusions

Men accorded more importance to potential side-effects when making decisions to pursue medical or surgical options than did women. Women viewed the probability that medical-surgical regimes would be effective as a more important factor influencing their decisions about these options than did men. The research underscored the importance of including both partners in counselling about infertility decisions. Nurses should encourage the couple to re-examine the forces influencing their treatment decision each time a new alternative is posed, especially by focussing on how stress influences the decision.

Freeman, E.W., et al. 1985. "Psychological Evaluation and Support in a Program of In Vitro Fertilization and Embryo Transfer." *Fertility and Sterility* 43: 48-53.

Subject

The psychological evaluation of patients participating in a university-based IVF-ET treatment program. It presents data on the couples' perceptions of their infertility and their psychological status at initial evaluation for IVF-ET treatment. It also provides baseline data for further longitudinal study of emotional factors in the treatment process and couples' responses to treatment outcomes.

Methodology

Subjects underwent an hour-long evaluation by a clinical social worker during their initial IVF consultation. Prior to the session, they completed a brief psychosocial questionnaire and, following it, the counsellor completed a global rating of each individual's ego strength, coping skills, and ambivalence about treatment. The Minnesota Multiphasic Personality Inventory (MMPI) then was completed at home by each partner and returned before treatment proceeded. Data were analyzed using descriptive statistical techniques.

Sample

The sample comprised 200 couples consecutively enrolled for IVF treatment. The women's mean age was 32 years; the men's, 34 years. Ninety-six percent were Caucasian. Their economic status was middle to upper class. Seventy-one percent of the women and 80 percent of the men had education beyond high school. Typically, both partners were employed and 66 percent had no children. Half had been infertile for four or more years. Forty-eight couples did not complete the MMPI.

Comments

Overall MMPI results were consistent with global assessments recorded by the counsellor after the initial evaluation. Reliability/validity/bias reduction not discussed.

Conclusions

Half the women and 15 percent of the men reported that infertility was the most upsetting experience of their lives. More women than men indicated that infertility treatment had changed their sexual relationships; two-thirds reported that sex had become less pleasurable. On the MMPI, about 29 percent of men and women had one or more elevated scale scores, suggesting dysfunctional emotional distress or personality difficulties. Half the sample had high scores on the MMPI Ego Strength scale, which indicated effective functioning and ability to withstand stress. T scores for

the Taylor Manifest Anxiety Scale were normal before treatment. Further longitudinal study is needed to define the emotional impact of procedures and reactions to treatment outcomes. The author emphasizes that the couples were evaluated before treatment; thus, anxiety scores reflect characteristic anxiety levels rather than response to stress.

Freeman, E.W., et al. 1987. "Emotional and Psychosocial Factors in Follow-Up of Women After IVF-ET Treatment." *Acta Obstetrica et Gynecologica Scandinavica* 66: 517-21.

Subject

Perceptions of treatment stress, decisions about further treatment, and the extent of resolution of the infertility crisis. Standard self-report instruments were used to assess emotional status, self-esteem, and marital adjustment.

Methodology

In this pilot study, telephone interviews using a semi-structured interview questionnaire were conducted by a skilled clinical social worker who had had no prior contact with the couples. Couples completed the Harris-Lingoes Subjective Depression and Taylor Manifest Anxiety scales from the MMPI, MAT, the Rosenberg Self-Esteem Scale, and the anxiety and depression factors of the Hopkins Symptom Checklist (HSCL).

Sample

The sample comprised 156 (from a pool of 246) women who had enrolled for treatment in an IVF-ET program. They were interviewed 15 months (mean interval) after their last program contact. The sample included an unsuccessful treatment group (n=82), a no-treatment group (n=37), and a pregnancy group (n=37). Self-report measures were returned by 90 women.

Comments

Comparison of enrolment data revealed no significant differences in the background of interviewed couples and those not contacted. Differences between the MMPI scores at enrolment of those who returned the assessments and those who did not were not statistically significant. Longitudinal data are needed to confirm and elucidate these findings.

Conclusions

Only about half the couples who did not achieve pregnancy decided to terminate treatment. Resolution of infertility was correlated with coping with infertility and with the decision to abandon treatment. Although most patients described treatment as extremely stressful, this did not result in

emotional distress or dysfunction following treatment, and psychiatric syndromes were infrequent.

Given, J.E., G.S. Jones, and D.L. McMillen. 1985. "A Comparison of Personality Characteristics Between In Vitro Fertilization Patients and Other Infertile Patients." *Journal of In Vitro Fertilization and Embryo Transfer* 2: 49-54.

Subject

To identify differences between infertile couples seeking help in establishing a family through an IVF program and infertile couples receiving medical treatment for infertility but not participating in an IVF program.

Methodology

Patients in an IVF program were compared with individuals undergoing fertility investigation and treatment other than IVF. Each subject was given the California Psychological Inventory (CPI) and a social history interview during which behavioural signs of anxiety were noted. The interview consisted of questions pertaining to the IVF clinic, the subject's attitude toward childlessness, marital adjustment, and social history and present life situation.

Sample

Seventy-five married individuals receiving medical infertility treatment. Twenty-nine women and 21 men were in an IVF program and 13 women and 12 men were undergoing fertility investigations. All participation was voluntary. Eleven IVF subjects and two non-IVF subjects did not complete the CPI; three subjects' tests were invalid. Four subjects completed the CPI but did not participate in the interview.

Comments

Reliability/validity/bias reduction not discussed.

Conclusions

The CPI profile indicated the IVF subjects had stronger characteristics of ambitiousness, creativity, and independence. No major differences were noted regarding the interview questions and behavioural ratings. Both groups viewed IVF as a possible infertility treatment; however, the IVF patients had certain personality characteristics that made them more likely to seek IVF. The hypothesis that the IVF subjects would receive a higher rating on anxiety and associated symptomatology from the behaviour rating list was not supported. Some IVF patients commented on how stressful it was to be in the program; however, some non-IVF patients also reported their situation and infertility problem as stressful.

Goodman, K., and B. Rothman. 1984. "Group Work in Infertility Treatment." *Social Work with Groups* 7 (1): 79-97.

Subject

The impact of infertility treatment on psychosocial functioning, reporting on group-session recordings of two infertility groups designed to help female patients manage infertility crises, sustain involvement in treatment, and prevent possible damaging psychological and interpersonal consequences of infertility.

Methodology

A model of group service was designed incorporating three sequential levels. In the first phase, two groups of six to eight patients agreed to meet with a worker for 90 minutes weekly for eight weeks. (Both groups extended this contract.) Sessions were tape-recorded and transcribed. No prescribed curricula or worker-directed, prearranged agenda was used. During the second phase, groups met on their own in the physician's office. These sessions also were recorded. The third phase involved less formal contact between group members and the worker.

Sample

Women who, having refused an invitation to participate in group sessions during their initial medical work-ups, decided to take part some time after beginning infertility treatment. No demographic information regarding the sample is provided.

Comments

Reliability/validity/bias reduction not discussed.

Conclusions

Several themes and processes surfaced throughout the groups' development and with the worker's intervention. The most significant of these are discussed. They include group building, interpersonal relations outside the group, managing medical treatment and knowledge sharing, marital relationships, alternatives to pregnancy, and the group worker-physician relationship. The results of group service cited suggest there are benefits to using a format that is process-oriented and low leader-directed. In addition, the value of the groups from their early intensive-support phase to their final networking stage was documented. The question of how to make group service more accessible and desirable in clinical infertility practice needs further attention.

Harper, R., E.A. Lenton, and I.D. Cooke. 1985. "Prolactin and Subjective Reports of Stress in Women Attending an Infertility Clinic." *Journal of Reproductive and Infant Psychology* 3: 3-8.

Subject

The stress of infertility clinic visits from the patient's point of view, and relating subjective responses to plasma prolactin levels in two samples attending for first-time infertility investigations.

Methodology

Two groups of patients were studied. Couples in the first group were asked to complete a Mood Adjective Checklist while waiting to see a gynaecologist. Each partner separately had her/his height, weight, and blood pressure recorded and blood samples taken. The women in the second group were assessed using STAI, before blood sampling and before seeing the gynaecologist. In both cases, prolactin was measured by radioimmunoassay from blood samples taken before the gynaecological examination.

Sample

The first group consisted of 20 consecutive couples. Eleven women and five men completed the checklist after blood samples were taken; all subjects completed it before seeing the gynaecologist. The second group consisted of 36 women attending the clinic consecutively. All completed the STAI on arrival, before blood sampling and before seeing the gynaecologist.

Comments

Reliability/validity/bias reduction not discussed.

Conclusions

Higher values of prolactin, measured before the gynaecological interview and examination, were found to coincide with subjective reports of stress and anxiety among female patients. Among men, the correlation between stress and anxiety and prolactin levels was positive but not significant. The anticipatory response was of physiological rather than pathological proportions, and none of the patients in either sample was found to have sustained hyperprolactinemia. Prolactin concentrations did not correlate with trait anxiety as measured by STAI. Efforts should be made to minimize stress in patients attending infertility clinics, in particular by providing more information.

Harris, A.B. 1989. "Examining Infertility as a Crisis: A Comparison Between Two Groups of Infertile Women Based on Treatment Status." Ph.D. dissertation, Fielding Institute.

Subject

The theory that infertility diagnosis and treatment constitute a crisis during which women demonstrate more emotional problems and sex-role conflict, as well as report less marital satisfaction, than women who have terminated such treatment.

Methodology

Subjects were administered a series of self-report measures, including (1) the STAI — Form Y; (2) the Depression Adjective Check List (DACL); (3) the Internal-External Locus of Control Scale; (4) the Personal Attributes Questionnaire (PAQ); (5) the Life Experience Survey; (6) the MAT; and (7) the Marital Closeness and Intimacy of Communication Interview. ANOVAs were calculated for each dependent variable.

Sample

Fifty-two infertile, Caucasian, married women aged 24-42 were selected from the active caseloads of several private obstetrical/gynaecological practices. Of these, 21 women were involved in medical treatment for infertility (primary); 19 others with primary infertility had terminated treatment at least one year before (resolved); and 12 women in treatment for secondary fertility were evaluated for heuristic purposes.

Comments

Equal numbers of women from each practice were studied. Measures of trait anxiety, trait depression, and other sources of life stress for each group were compared to ensure that differences did not rely on underlying personality traits or other stress. The reported reliability and validity of each instrument used was discussed.

Conclusions

Women involved in infertility treatment present different psychological profiles than women no longer involved in such treatment. Women in the primary group experienced significantly more state anxiety than women in the resolved group. Further analysis suggested that state anxiety might be influenced more by the younger age of those in the primary group than by their treatment status. When age was statistically controlled, women in that group had significantly higher scores on the PAQ MF scale (a measure of emotional vulnerability) than women in the resolved group. Denial proved to be significantly stronger in the primary group than in either of the others. Themes emerging from the open-ended interview indicated that women had concerns regarding the medical process, relationship issues,

emotional ups and downs, and gaining a spiritual understanding of their experience.

Harrison, R.F., A. O'Moore, and R.R. O'Moore. 1981. "Stress and Artificial Insemination." *Infertility* 4: 303-11.

Subject

Infertility investigations and treatment are stressful to couples; however, this is particularly true for women undergoing DI and homologous AI. The stress may give rise to anovulation, which has led some inseminators to routinely use agents such as clomiphene citrate to ensure normal cycling. This study examines the extent of this problem, whether it is predictable, possible reasons for it, and whether present therapy is apt and adequate.

Methodology

A consecutive series of normal women undergoing AI because of azoospermia were followed throughout their therapy. They were reviewed monthly for a year. If anovulation developed, clomiphene citrate was prescribed. The final 10 patients underwent premenstrual psychological assessment before starting therapy. Four tests were used: the STAI; the Manifest Anxiety Scale; the anxiety factor in the Sixteen Personality Factor test; and the neuroticism factor and lie score in the Eysenck Personality Questionnaire. Controls were also used.

Sample

The sample consisted of 30 women attending for DI because their partners had azoospermia. The clinical controls were 10 consecutive couples with psychosexual problems who were practising AI at home. Psychological controls were eight fertile couples who underwent the same psychological studies as 10 of the patients.

Comments

Reliability/validity/bias reduction not discussed.

Conclusions

Eighty percent of hospital-treated patients achieved pregnancy as did 90 percent of self-inseminators. Forty-two percent of hospital-treated patients who became pregnant needed clomiphene citrate. This was necessary in only 12 percent of self-insemination successes. Mean anxiety scores show the insemination group to be under greater stress than the fertile controls in nearly all tests. Comparison between the anxiety scores of the four hospital-treated patients tested who did not develop ovulation problems and the six who needed clomiphene citrate showed no significant differences. There were no significant differences between the five

hospital-treated patients who became pregnant and the five who did not in any of the mean anxiety scores. It may be the environment in which therapy takes place rather than the treatment itself that results in extra stress and possible anovulation.

Harrison R.F., R.R. O'Moore, and A.M. O'Moore. 1986. "Stress and Fertility: Some Modalities of Investigation and Treatment in Couples with Unexplained Infertility in Dublin." *International Journal of Fertility* 31: 153-59.

Subject

The role of stress in infertility and its treatment in various groups of couples with unexplained infertility. Findings were obtained using a simplified profile of stress markers based on basal prolactin estimations and psychological measurements.

Methodology

Various psychological and hormonal stress markers were examined. A simplified stress profile was developed, containing aspects of STAI, the Manifest Anxiety Scale, the Sixteen Personality Factor Test, and the Personality Questionnaire, coupled with at least four basal estimations of prolactin status.

Sample

Twenty-two couples experiencing infertility for at least three years were compared with 10 fertile controls matched for age and socioeconomic group using the simplified stress profile. In the case of infertile couples, the psychological component was carried out after full infertility work-up had found them normal. All couples were permitted to complete the questionnaires at home.

Comments

Data analysis suggests that, if the role of stress in infertility is to be discovered and addressed, more sensitive diagnostic parameters need to be developed. Both psychological and biochemical components of the simplified stress profile were found to apply in the clinical context. Reliability/validity not discussed.

Conclusions

Infertile couples had higher mean anxiety scores on all emotional factors tested than controls. A subgroup of women were identified as having significantly high psychological stress scores and intermittent elevations of prolactin. This group was effectively treated with clomiphene citrate and bromocriptine. Attention to treatment failure and success suggests that optimum benefit to patients might rely not only on providing

good clinical ambience and pharmacological preparations, but also relaxation therapies such as autogenic training, which significantly lowered psychological and biochemical stress marker scores.

Haseltine, F.P., et al. 1985. "Psychological Interviews in Screening Couples Undergoing In Vitro Fertilization." *Annals of the New York Academy of Sciences* 442: 504-22.

Subject

(1) To produce a general demographic and psychological profile of patients undergoing IVF for baseline comparisons with later work; (2) to test specific psychological screening instruments to determine whether correlations exist between psychological profiles and pregnancy outcomes; and (3) to determine what aspects of the IVF protocol cause major problems for couples.

Methodology

Couples received pre-treatment interviews and psychological testing upon admittance to an IVF program and were retested on several measures at ET. The semi-structured pre-treatment interview highlighted questions related to the patient's infertility. Psychological test/structured rating scales included: (1) STAI; (2) Differential Emotion Scale; (3) Life-Events Scale; (4) Marlowe-Crowne Social Desirability Scale combined with Taylor Manifest Anxiety Scale; (5) a shortened MMPI; and (6) Side-Effects Checklist.

Sample

Seventy-four couples consecutively admitted to the IVF program. Female patients were on average 33.4 years old, 95 percent were white and 50 percent were Catholic. The men averaged 34.7 years old and 43 percent were Catholic. The women had tried to conceive for an average of 6.7 years. Seventy-five percent had had previous infertility-related surgery.

Comments

Administered tests were chosen after a three-month trial during which 30 couples were tested at different points in the protocol. To reduce bias, interviews and tests were made part of the IVF protocol, not part of application procedures.

Conclusions

The study provided initial profiles of couples seeking IVF. A comparison of interview data with objective data suggested that women are stressed by infertility but are reluctant to report their stress for fear they will be dropped from the protocol. In conjunction with the results of the Marlowe-Crowne/Taylor tests, this finding suggests that these women may

be at greater risk for psychosomatic illness because of their tendency toward repressed anxiety. Three cases illustrating the stress experienced by couples in the IVF program are discussed briefly. Stress resulted from the program's demands, the surgery involved, and failure to become pregnant. It also was found that the staff social worker played an important role in educating couples and explaining protocols during the initial contact and providing ongoing support and counselling. Too few patients became pregnant to enable analysis of that subgroup.

Hirsch, A.M., and S.M. Hirsch. 1989. "The Effect of Infertility on Marriage and Self-Concept." *Journal of Obstetric, Gynecologic, and Neonatal Nursing* 18: 13-20.

Subject

Two groups of subjects (couples seeking medical treatment for infertility and couples not yet attempting to conceive) completed questionnaires assessing the impact of infertility on their marriages and self-concept.

Methodology

Three questionnaires were used: the investment/press questionnaire (designed by the experimenters); the Bem Sex-Role Inventory; and the Hudson Clinical Measurement Scales.

Sample

Sample consisted of 92 subjects, divided into two groups. Experimental group comprised 58 subjects (30 women and 28 men; mean age 32) derived from an initial sample of 92 seeking treatment at an infertility clinic. Control group comprised 34 volunteer subjects (17 married couples; mean age 26) derived from an initial sample of 81 potential controls. Among the control group, 24 were college students and the rest were professionals or white-collar workers.

Comments

The investment/press questionnaire was not assessed in terms of validity and reliability; the factual nature of questions did not necessitate reliability or validity assessment. Construct validity was obtained by interviewing health professionals working with infertile couples. Bem inventory and Hudson scales are discussed regarding measures of reliability and validity.

Conclusions

Infertile individuals experienced greater dissatisfaction with themselves and their marriages. Women experienced greater discontent over time and had greater emotional investment than men. Infertile

couples labelled non-communicators were found to be affected even more by infertility. As fertility work continued, men seemed to adapt better to the intervention, while women were increasingly affected.

Hofmann, R., A. Jeschke, and B. Jeschke. 1985. "Problems of Breaking off Sterility Treatment by Patients." *Zentralblatt für Gynäkologie* 107: 294-99.

Subject

Patients' reasons for discontinuing infertility treatment at the Wilhelm-Pieck University, Rostock, Germany.

Methodology

No details provided.

Sample

Two hundred and eighteen clinic patients who discontinued treatment were asked to complete questionnaires. From 103 questionnaires, 194 individual responses were recorded.

Comments

Article in German. English abstract and references only on file.

Conclusions

On average, more than one reason led to the decision to cease treatment. Personal problems, such as unsuccessful treatment, advanced age, too high a demand on time, marital conflicts, stimulant consumption, and diseases were prevalent. Pregnancy, adoption, occupational problems, and a problematic physician-patient relationship also were cited.

Holmes, H.B., and T. Tymstra. 1987. "In Vitro Fertilization in the Netherlands: Experience and Opinions of Dutch Women." *Journal of In Vitro Fertilization and Embryo Transfer* 4: 116-23.

Subject

To understand women's motivations for participating in IVF by exploring their attitudes toward having children, to discover patients' reactions to steps in the treatment, and to learn the views of laypersons on the ethical questions surrounding IVF.

Methodology

Four groups of women were asked to respond anonymously to a questionnaire: (1) women who had had babies as a result of IVF; (2) women who had undergone one or more unsuccessful attempts and were awaiting a chance to try again; (3) women on an IVF waiting list; and (4) women who had had two or more children. All groups received 34 questions regarding attitudes toward motherhood and ethical issues. Groups 1 and 2 received 17 questions regarding their experiences of IVF, and group 2 received six more questions regarding their feelings after a failed attempt. Responses were statistically analyzed.

Sample

Seventy-eight of 93 questionnaires were returned: 14 (88 percent) from group 1; 15 (88 percent) from group 2; 32 (80 percent) from group 3; and 17 (85 percent) from group 4. About one-third of respondents wrote additional comments.

Comments

Reliability/validity/bias reduction not discussed. Charts provide an overview of the questions posed and answers obtained. It was noted that group 4 does not meet the strict standards for a sociologically matched control group. Women who decided to discontinue treatment after undergoing one or more IVF cycles were not surveyed.

Conclusions

Most women surveyed were strongly positive toward having children and toward IVF, but fewer fertile than infertile women believed that "a child of one's own" was a right and that government insurance ought to cover IVF. Nearly all patients were satisfied with their clinical treatment and would recommend IVF. Most women favoured gamete donation and surrogate gestation, but fewer fertile than infertile women approved experiments with "spare" embryos or the implantation of donated embryos. All IVF programs should assign high priority to improving psychological support for couples under IVF treatment. As they begin, couples should receive written information that emphasizes the low chance of success.

James, B., and P.F. Hughes. 1982. "Psychological Well-Being as an Outcome Variable in the Treatment of Infertility by Clomiphene." *British Journal of Medical Psychology* 55: 375-77.

Subject

The paper examines and quantifies the psychological well-being of women suffering from anovulation, after attempted treatment by clomiphene citrate.

Methodology

All patients were sent the short form of Affectometer I (Kammann et al. 1979). The criterion "happiness" was judged a positive outcome measure. The Affectometer consists of 24 sentence items and 24 adjective items all shown to contribute to a subjectively experienced global state of happiness. Subjects also were asked to rate themselves on a single seven-point scale of overall happiness, with reference to the previous year.

Sample

Thirty-one cases of female infertility involving the use of clomiphene citrate were identified in the records of two consultant gynaecologists, one in hospital and the other in private practice. Thirty patients agreed to participate. The 12 patients who had not conceived had taken clomiphene citrate for not less than 12 months. Three patients, all in the negative-outcome group, failed to return their questionnaires despite earlier agreement and follow-up by mail.

Comments

Validity and reliability of the Affectometer has been demonstrated in the general population. Its internal consistency indicated its superiority over similar alternatives. Bias reduction not discussed.

Conclusions

There was an essential similarity in terms of happiness between the positive- and negative-outcome groups, particularly when excluding two patients whose low scores could be reasonably explained by recent adverse events. Failure of a positive outcome (i.e., pregnancy) to provide solutions to existing psychological or interpersonal problems may have resulted in disillusionment of the positive-outcome group. Survey results support comments by other authors suggesting that resolution of the "problem" is influenced as much by the individual's adaptive capacity as by treatment outcome. This raised questions about the degree to which investigation and treatment should be pursued. Two other factors seemed important in arriving at a successful psychological outcome: awareness by the attending physician and sensitivity by both male and female partners to long-held fantasies, role expectations, etc.

Lalos, A., et al. 1985b. "The Psychosocial Impact of Infertility Two Years After Completed Surgical Treatment." *Acta Obstetrica et Gynecologica Scandinavica* 64: 599-604.

Subject

To investigate the psychological and social impact of infertility in couples two years after unsuccessful surgical treatment for tubal infertility and to describe their expectations and hopes as well as their need for professional psychosocial counselling.

Methodology

All participants attended interviews about one month before and two years after reconstructive tubal surgery. Partners were interviewed separately on the same day. A standardized questionnaire and semi-structured interviews were used, focussing on marital relationships, social and sexual life, mental health, other solutions to infertility, and the need for professional psychosocial counselling. A symptom checklist was used to record mental symptoms in the preceding six months. Participants also completed the Eysenck Personality Inventory Form A. Statistical significances were assessed.

Sample

During one calendar year, all women who were to undergo surgical treatment were asked to participate. All 30 women and 29 men were willing to cooperate. The average duration of infertility was five years; the mean and median age of the women was 29 years; of the men, 30 years. Four women had a normal pregnancy within two years of surgery and were excluded from the analysis. One man did not attend the follow-up interview. Twenty-four couples were included in the study.

Comments

It was noted that the study's findings should not be interpreted as representative of and comprehensive for all infertile couples since the sample is small and contains a rather specific group of individuals. Reliability and bias reduction not discussed.

Conclusions

Most couples studied considered their marital relationship to be very good or good both before and after the operation. Concerning partners' feelings toward one another, a deterioration was noticed, especially among the men. The couples' sexual life also was thought to have deteriorated during the two years after the operation, especially by the women. Regarding attitudes toward other peoples' children, men often tried to approach other people's children while women avoided them. The emotional effect of infertility was most pronounced among women. Feelings

of grief among the men had intensified two years after the spouse's unsuccessful surgical treatment. Most (70 percent) couples had not even tried to solve their fertility crisis two years after surgery. Acceptance of childlessness is sometimes hampered by persistent hope for a miracle. In many cases, the need for professional support was apparent.

Lalos, A., et al. 1985c. "Psychological Reactions to the Medical Investigation and Surgical Treatment of Infertility." *Gynecologic and Obstetric Investigation* 20: 209-17.

Subject

The psychological and social effects of long-lasting medical investigation and treatment of infertile couples.

Methodology

A standardized questionnaire was completed and semi-structured interviews were carried out. Four individual interviews were performed with the women and two with the men during two years.

Sample

During one year (1981), all women who were to undergo surgical treatment for infertility at the author's institution were asked to participate in the study; all subjects were willing to participate. Thirty women diagnosed with tubal damage and 29 men were followed with repeated interviews over two years. Mean age of the women was 29 years (range 21-34); of the men, 30 years (range 24-53).

Comments

Reliability/validity/bias not discussed.

Conclusions

Negative effects on sexual life were recorded by all individuals and were associated with the planning of intercourse. Semen analysis was psychologically difficult for half of the men and feelings of shame and degradation were common. Fear and anxiety increased before reconstructive tubal surgery and post-operative depression was observed in 10 women. Most couples overestimated their chances of having a child and half of them expected a pregnancy within a few months. After two years, the need for professional support and counselling had increased. Medical procedure has psychological side-effects in infertile couples and may provoke anxiety. Investigation should be comprehensive and short. Psychologically traumatic investigations should be used with caution.

During somatic investigation and treatment, repeated discussions about marital and sexual life should be initiated and psychological counselling offered.

Lalos, A., et al. 1986. "Depression, Guilt, and Isolation Among Infertile Women and Their Partners." *Journal of Psychosomatic Obstetrics and Gynaecology* 5: 197-206.

Subject

Longitudinal study to indicate whether and to what extent psychological reactions compatible with a crisis pattern could be identified among infertile women with tubal damage and how infertility affected their partners.

Methodology

During a period of two years, four interviews were performed with the women and two with the men. Semi-structured interviews took place with each partner separately a few weeks before surgery and two years after, focussing on the psychosocial effects of infertility. Participants also completed the Eysenck Personality Form A. The woman was interviewed soon after the surgery and about one month later at second-look laparoscopy. The main purpose of these interviews was to register emotional status and psychological reactions related to the operation and laparoscopy. Statistical analysis of responses was undertaken.

Sample

Thirty women who were to undergo surgical treatment for infertility agreed to participate, along with 29 of their partners. The mean age of the women was 29 years; of the men, 30 years; the average duration of infertility was five years; and the mean duration of the marriage was seven years. After at least one year of unsuccessful efforts to conceive, all had undergone routine infertility investigations. Twenty-six women and 24 men completed the study.

Comments

Reliability/validity/bias reduction not discussed.

Conclusions

Most recorded symptoms could be classified in terms of depression, guilt, and isolation. Women generally manifested more depressive symptoms than men, who often suppressed or even denied emotional reactions. Guilt feelings were more common among women than men. Social isolation often developed among the infertile women and their partners. Crisis reactions specific to infertility often were prolonged and repeated. The protracted medical procedure, with sudden fluctuations of

feelings, unrealistic expectations, and depression, may increase the risk of neurotic disturbances. To cope with the crisis of infertility, couples require supportive counselling, separately and together, during investigation and medical treatment.

Leiblum, S.R., E. Kemmann, and M.K. Lane. 1987a. "The Psychological Concomitants of In Vitro Fertilization." *Journal of Psychosomatic Obstetrics and Gynaecology* 6: 165-78.

Subject

Pilot study undertaken to identify and determine the psychological and physical concomitants of various IVF phases, and to assess the reactions of wives and husbands throughout and following one or more IVF cycles. A stage model of characteristic reactions to each phase of IVF is presented.

Methodology

A pre-IVF questionnaire assessed relevant demographic and background information. Participants also completed: (1) the short form of MAT, (2) the Profile of Mood States (POMS), and (3) the Rotter Internal-External Control of Reinforcement Scale (I-E scale). Five weeks after beginning IVF protocol, a post-IVF questionnaire assessed the overall stress of the IVF procedure and reactions to menotrophic drugs, ovum transfer, feelings following transfer, and the resumption of menses. Couples also completed another MAT and POMS.

Sample

Fifty-nine couples who completed at least one cycle of IVF and returned both pre- and post-IVF evaluation questionnaires. Data collected over 26 months from 1983 to 1985. Pre-IVF questionnaires collected from 158 wives and husbands.

Comments

Based on statistical comparison of all pre-treatment variables, there appeared to be no significant difference between those completing pre-IVF questionnaires only and those included in the study, with the exception of a single POMS score. Reliability/validity not discussed.

Conclusions

Results revealed that couples tended to be overly optimistic about the likelihood of achieving an IVF pregnancy despite admonitions concerning the low probability of success. Couples tended to rate the procedure as moderately stressful. Common reactions to menotropin administration were fatigue, weight gain, headaches, and moodiness. Sadness, anger, and depression were common reactions to unsuccessful IVF and were significantly more pronounced in wives than in husbands. Despite failure to

conceive, most couples reported satisfaction at having attempted IVF. Adequate attention must be directed to the psychological and physical aspects of this option.

Leiblum, S.R., et al. 1987b. "Unsuccessful In Vitro Fertilization: A Follow-up Study." *Journal of In Vitro Fertilization and Embryo Transfer* 4: 46-50.

Subject

To investigate how infertile women recalled their IVF experiences and to assess their outlook regarding future reproductive options.

Methodology

A follow-up questionnaire was sent to women who had unsuccessfully completed one or more IVF trials. The questionnaire consisted of nine objective questions. The latter questions focussed on whether or not the woman felt she had resolved the "infertility crisis" and invited the woman to write down any thoughts about her experiences with infertility, the IVF program, and her current life.

Sample

Eighty-three women were mailed a questionnaire, and 28 of these were returned — a 34 percent response rate. Of these respondents 46 percent had undergone only one IVF attempt, 18 percent had undergone two attempts, 29 percent had undergone three attempts, and 7 percent had undergone four attempts. The mean time elapsed since their last attempt was 8.4 months.

Comments

Reliability/validity/bias reduction not discussed.

Conclusions

Most women cope effectively with the disappointment of unsuccessful IVF and, given the opportunity, would repeat the experience. Thirty-three percent of respondents had applied for adoption and 11 percent had already adopted a child, which suggests that terminating attempts to achieve biological parenthood permits couples to explore other options more actively. However, 44 percent indicated they were still trying to conceive biologically eight months or more following unsuccessful IVF. Ninety-three percent of women said they would be receptive to any innovative method for achieving pregnancy, and 37 percent would require a success rate of 20 percent or more to consider undergoing such a treatment. The subgroup of women who have difficulty abandoning the idea of biologically conceiving

may require sensitive psychological support from IVF personnel during the active phase of the procedure and referral to other mental health professionals.

Link, P.W., and C.A. Darling. 1986. "Couples Undergoing Treatment for Infertility: Dimensions of Life Satisfaction." *Journal of Sex and Marital Therapy* 12: 46-59.

Subject

To investigate the perceived life, marital, and sexual satisfaction of married couples undergoing infertility treatment. It sought to determine their levels of satisfaction in various life domains, the relationship between husbands' and wives' perceptions of satisfaction, and the relationship among these various dimensions of life satisfaction.

Methodology

The sample was obtained through contact with physicians and through advertisement in a national newsletter for infertile people. A survey research design was used. Husbands and wives were asked to complete the survey separately and return it anonymously. The instruments used were three scales from the Clinical Measurement Package: the Generalized Contentment Scale, the Index of Marital Satisfaction, and the Index of Sexual Satisfaction. Statistical procedures were employed to examine the relationships under investigation.

Sample

Thirty couples identified from contacts with physicians and 14 from national advertisement. Data were also obtained from 17 wives whose husbands did not participate. Respondents were aged 20-52 years. Most respondents were white and highly educated and were in their first marriage. Fourteen couples already had children; none had more than two. They had been treated for an average of 2.4 years.

Comments

It was noted that each index from the Clinical Measurement Package has a reliability of .90 or better and has good content, concurrent, factorial, discriminant, and construct validity. Concern was expressed that the sample was obtained through two sources.

Conclusions

Wives had a significantly lower level of satisfaction with life than their husbands, and there were significant relationships between husband-wife pairs for both marital and sexual satisfaction. In comparison to paired wives, the 17 wives whose husbands chose not to respond to the survey indicated higher levels of dissatisfaction in all three dimensions. Most of

this group's scores indicated clinical levels of depression. It was evident that individuals, especially women, undergoing infertility treatment experienced stress in various life areas. It is recommended that clinicians encourage the couple's acceptance of themselves as they are, create a supportive environment during treatment, and direct them to other sources of assistance and support.

Lukse, M.P. 1985. "The Effect of Group Counseling on the Frequency of Grief Reported by Infertile Couples." *Journal of Obstetric, Gynecologic, and Neonatal Nursing* 14 (Suppl.): 67s-70s.

Subject

To determine if an infertility group-counseling program could reduce the frequency of grief responses.

Methodology

A 26-item questionnaire was developed, adapted from the Differential Emotions Scale, the Index of Sexual Satisfaction, the Index of Self-Esteem, and the Index of Marital Satisfaction. Its purpose was to collect data concerning feelings related to loss of control, anger, self-concept, frustration, and the marital and sexual relationship. Each person completed the questionnaire at the beginning of the first counselling session and again during the final session. Data were analyzed using the Wilcoxin matched pairs, signed-ranks test.

Sample

Fourteen couples and one woman who attended the program without her spouse. The subjects had tried to conceive for one year or longer and were then involved in infertility evaluation and/or treatment. They were referred to the group by physicians, self-referral, or local agency representatives.

Comments

The internal reliability and validity of the instruments adapted for questionnaire use were discussed. An attempt was made to ensure construct validity by having five medical and educational professionals and three infertile couples review and report the relevance of questionnaire items. Bias reduction not discussed.

Conclusions

Infertility counselling reduced the self-reported symptoms of grief experienced by some infertile couples. Women improved in all areas of grief categories, while men remained essentially the same. Similarly, women reported a significant improvement in their self-concept, whereas men remained essentially the same. The couples reported no significant

changes in their feelings about their marital and sexual relationships after counselling.

McGrade, J.J., and A. Tolor. 1981. "The Reaction to Infertility and the Infertility Investigation: A Comparison of the Responses of Men and Women." *Infertility* 4: 7-27.

Subject

The emotional impact of infertility on self-worth, self-image, and sexuality, and its perceived influences on couples' sexual function. Focus directed to the effects of investigation and physician-directed coitus on couples' marital and sexual health. Significant differences between male and female respondents are enumerated and discussed.

Methodology

Charts of 369 infertility patients evaluated from January 1975 to December 1979 were reviewed. Only those who completed a basic survey and were involuntarily infertile for at least one year were studied. A 30-item questionnaire was developed using a simple agree/disagree format. Separate questionnaires were sent to husbands and wives and anonymity was suggested. Those who succeeded eventually in having a child and those who did not were evaluated. Group differences were subjected to statistical analysis.

Sample

Of 369 couples whose charts were reviewed, 200 couples met the study criteria. One hundred and twenty-six completed the questionnaire — a 63 percent response rate. Of these, 82 had succeeded in having a child, while 44 had not.

Comments

A copy of the questionnaire used is appended to the article. Care was taken to balance positively and negatively worded items to minimize a particular response set. Validity/reliability not discussed.

Conclusions

Large numbers of both men and women recognized the emotional distress, tension, and strain associated with infertility. Many patients' self-image seemed to be affected, but women suffered a greater incidence of injury to self-esteem than men. A high incidence of disturbed sexual function was reported by all groups. Again, women were at greater jeopardy than men and were more likely to question their sexuality. A long-standing concern with the effects of investigation is validated by the admitted deterioration of the patient's sex life as fertility evaluation progressed. It may be possible to formulate a profile that would permit

identification and treatment of patients most susceptible to dysfunction caused by emotional factors.

Macourt, D.C., and G.R. Jones. 1977. "Artificial Insemination with Donor Semen." *Medical Journal of Australia* (7 May): 693-95.

Subject

The cases of 53 couples referred for DI were reviewed. Treatment results and the parents' psychological and legal considerations are discussed.

Methodology

The psychological and legal aspects of DI were discussed at length and in depth with all couples requesting DI. One of the authors managed 40 of the resulting pregnancies (including five abortions) and followed up 23 of them (nine women were still pregnant at the time of writing). In all cases, the husband and wife were seen individually and together.

Sample

A total of 53 couples were referred for DI. Three couples were not accepted for treatment after an initial consultation, one because of severe tubal disease and two because one or both partners had mixed feelings toward the procedure. Three patients were referred for psychiatric consultation but later were accepted for treatment. All patients requested DI in preference to adoption. Five couples dropped out after DI commenced.

Comments

Reliability/validity/bias reduction not discussed. Focus of the paper is the DI procedure and a general discussion of the procedure's psychological and legal implications.

Conclusions

Of 45 patients who continued treatment, 36 conceived and nine remained in treatment at time of writing. There were 43 pregnancies resulting in 29 live births and five first trimester abortions, with nine patients more than 20 weeks pregnant. No feelings of hostility or resentment toward the child or other spouse were elicited. All parents accepted the child as their own. The pregnancy, delivery, and puerperium appeared to have no more emotional sequelae than observed in patients conceiving naturally. The excellent results may have been due to the considerable thought put into the matter by couples before they were seen, and that they requested DI in preference to adoption.

Mahlstedt, P.P., S. MacDuff, and J. Bernstein. 1987. "Emotional Factors and the In Vitro Fertilization and Embryo Transfer Process." *Journal of In Vitro Fertilization and Embryo Transfer* 4: 232-36.

Subject

To describe patients' acknowledged emotional state when they began the IVF-ET process and the emotional experience of the procedures themselves.

Methodology

Data collected from a 31-item, self-administered questionnaire developed with input from the staff of three programs involved in the study. Some questions were designed in a Likert format to permit statistical analysis; others were open-ended to enable variety and completeness of response. Demographic information also requested. Results were tabulated using the E-Z STAT program, and STATSOFT was used to analyze data by *t*-test and chi-square techniques.

Sample

Three IVF programs in Houston, Texas, participated. All patients entering these programs between December 1984 and August 1985 were asked to participate during an initial orientation meeting with the IVF team coordinator. Two hundred and forty-six questionnaires were distributed and 94 were returned — a 38 percent response rate. Sixty-three percent of the respondents were females and 37 percent were males. Their median age was 34 years (range 24-45). For 77 percent of respondents, this was the first IVF experience.

Comments

Response rate was lower than desirable; however, it appears the sample was similar to the general population of infertility patients demographically and behaviourally. Few differences were noted between pregnant and non-pregnant groups in their perceptions of the effects of infertility, reducing concern about a response bias based on reaction to a failed medical procedure.

Conclusions

At the IVF procedure, 77 percent of the population reported that infertility was still a painful concern, not something with which they had learned to live. A sense of loss of control left them vulnerable to the intense stresses of IVF. For many, the IVF-ET procedures were like an emotional roller coaster; they experienced wide-ranging feelings during a brief time. Emotional strain was a major consideration influencing their decisions to repeat or abandon IVF. Patients indicated specific services that staff could provide to reduce the stress of the procedures.

Manuel, C., M. Choquet, and J.-C. Czyba. 1983. "Aspects sociaux, médicaux et psychologiques des grossesses et accouchements des mères par I.A.D." In *Aspects psychologiques de l'insémination artificielle*, ed. C. Manuel, and J.-C. Czyba. Villeurbanne (France): Simep.

Subject

Examined the psychological and medical aspects of DI. Parents were interviewed 6 months, 18 months, and 3 years after conception by DI.

Methodology

Derived from that used by Choquet et al. (1982) in a study of psychological and emotional development. Additional questions related to the patient's experience of infertility and treatment were added. Patients were interviewed using the revised questionnaire 3 months, 18 months, and 3 years after conception by DI. Their responses were compared with those of subjects interviewed in the study by Choquet et al.

Sample

One hundred and nine couples who had become parents as a result of DI using frozen sperm. They were registered with CECOS Lyon. Professionals and the middle class were over-represented in the sample. Most women were employed outside the home. The couples also tended to be older than most first-time parents.

Comments

The study was probably biased since it relied on individuals' accounts of past experiences, which could be expected to be unreliable. No discussion of reliability and validity.

Conclusions

DI mothers reported significantly higher rates of health problems and medical treatment during their pregnancies. In most cases, children were delivered by Caesarian section or with forceps; however, children conceived as a result of AI by donor (AID) were no more likely to be underweight, premature, or born with birth defects than other children. DI mothers appeared more anxious than average, and their doctors were more likely to intervene in their pregnancies. A greater percentage of DI mothers breast-fed their babies and for longer periods than other mothers. Fathers of DI children tended to fear the social stigma associated with DI and the possibility that their children would not resemble them. The absence of increased medical risks in pregnancies resulting from DI should be made clear to doctors and patients to help curtail unnecessary interventions in pregnancy and childbirth and maternal stress during pregnancy.

Mao, K., and C. Wood. 1984. "Barriers to Treatment of Infertility by In-Vitro Fertilization and Embryo Transfer." *Medical Journal of Australia* (28 April): 532-33.

Subject

To test whether stress level is a major cause of patient withdrawal from the Monash-Epworth IVF Program at Queen Victoria Medical Centre, Melbourne, Australia.

Methodology

The study was carried out in two parts. Initially, informal interviews were conducted with clinical staff members and IVF patients to identify the major sources of personal and administrative problems and dissatisfaction. From this list, 19 problems were identified and included in a structured questionnaire. The questionnaire was mailed to patients who had undergone at least one cycle of IVF but left the program without achieving pregnancy. Respondents rated the importance of each factor in their decision to leave the program.

Sample

Questionnaires were sent to 121 patients, and 91 were returned. The demographics of the 91 respondents were similar to those of other IVF patients (i.e., their mean age was 33 years, most had been infertile for more than five years, and most had no living children).

Comments

Reliability/validity/bias reduction not discussed.

Conclusions

Eighty-one percent of patients expressed satisfaction with their treatment. Sixty-one percent wished to re-enter the program later. Cost and psychosocial stress were found to be important reasons for discontinuing treatment, while living too far away and clinical failure also were frequent contributors. The external influences of the mass media or a change in attitude toward childbearing were not often important reasons for discontinuing treatment. The results indicated that more intensive patient counselling before admission to the program is required. The likely total cost, rather than the cost per treatment cycle, needs to be clarified, and patients should be warned about and advised on coping with the social and psychological stresses involved.

O'Moore, A.M., et al. 1983. "Psychosomatic Aspects in Idiopathic Infertility: Effects of Treatment with Autogenic Training." *Journal of Psychosomatic Research* 27: 145-51.

Subject

Stress levels before and after autogenic training in 15 couples infertile for at least two years. Potential stress markers were: plasma prolactin; total urinary free cortisol and catecholamines; and four psychological tests: STAI, Taylor Manifest Anxiety Scale, Cattell Sixteen Personality Factor questionnaire, and Eysenck Personality Questionnaire. A control group of 10 normal couples was included.

Methodology

The day before their first visit, the couples collected 24-hour urine samples. The psychological profile was measured during the visit and blood was taken for prolactin estimation. For the psychological assessment, the four self-report tests described above were used. Patients undertook an eight-week course of autogenic training followed by two months' practice, then they were reassessed. Test results were statistically analyzed.

Sample

Fifteen couples infertile for more than two years. All had undergone eight fertility investigation procedures (listed). The mean age of the women was 32.1 years and the mean length of infertility was 6.7 years. Ten control couples, who had had no difficulty conceiving and were not on hormonal therapy, also were studied. Their mean age was 32 years. The results presented are for 11 couples, as four couples did not complete the autogenic training.

Comments

Reliability/validity/bias reduction not discussed.

Conclusions

Psychological tests indicated that the infertile women were more prone to anxiety and guilt feelings, more introverted, and tenser than female controls. The comparative data of the male patients and controls suggest no differences in their levels of anxiety, extroversion, or guilt-proneness. It should be recognized, however, that the husbands of infertile women showed considerable defensiveness. Autogenic training provided a suitable means of reducing anxiety in these patients, making them more assured and confident, though this relationship was noted to be weak. A higher mean prolactin level was found in the infertile women than in the controls, but it was reduced, in tandem with decreased anxiety scores, following treatment.

Ouellette, F.-R. 1988. "L'expérience de l'infertilité féminine vécue sous assistance médicale." *Sociologie et sociétés* 20 (1): 13-32.

Subject

Women's experience of infertility, with special emphasis on social and cultural factors. The authors argued that the viewpoint of infertile women must be taken into account in the debate surrounding the new reproductive technologies. The biomedical approach to infertility as well as the social and cultural context in which these women find themselves have a tendency to define recourse to assisted procreation techniques as the only possible alternative. This makes any challenge to the process of medical aid difficult once it is under way.

Methodology

Interviews were conducted with women undergoing treatment at fertility clinics in Montreal, Quebec, and Quebec City, Quebec. Each woman was asked about her experience of infertility investigation and treatment to date. A semi-structured interview format was used to examine the biomedical, social, cultural, psychological, and temporal/chronological dimensions of infertility.

Sample

Thirty-two women in treatment at fertility clinics were interviewed. In general, the women were better educated (50 percent with post-secondary education) and more were employed (71 percent) than a random sample of Quebec women of the same age. They were 21-39 years old. Subjects had undergone treatment for 1 month to 12 years, 41 percent for 4 years or more.

Comments

Reliability/validity/bias reduction not discussed.

Conclusions

In general, women reported that infertility treatment was a longer process and involved more medical treatment than expected. It transformed every aspect of their lives. Laparoscopy was the most serious medical procedure undertaken and caused much anxiety. Subjects voiced concerns about the impersonal treatment they received in clinics and difficulties associated with acquiring adequate information. One-quarter of the women foresaw the break-up of their relationship, related to changes brought about by the single-minded quest for a child. Few women surveyed waited as long as two years of unprotected intercourse before seeking treatment. A pattern of unquestioning obedience to the dictates of medical professionals, encouraged by social and cultural expectations, was noted. The author argued that a more holistic, woman-centred approach to infertility research and treatment is needed.

Reading, A.E., C.M. Sledmere, and D.N. Cox. 1982. "A Survey of Patient Attitudes Towards Artificial Insemination by Donor." *Journal of Psychosomatic Research* 26: 429-33.

Subject

An evaluation of psychological factors associated with attending a DI clinic. Anxiety level before each insemination was monitored to ascertain the level of stress involved and to identify patterns of anxiety change over successive treatment cycles and relate these to the occurrence of pregnancy. Attitudes toward insemination and childlessness were assessed before and after treatment.

Methodology

Before treatment, women were interviewed and completed a number of attitudinal and psychological measures: (1) the trait anxiety scale; (2) Maudsley Marital Questionnaire, and (3) Eysenck Personality Questionnaire. Before insemination over six successive treatment cycles or up to the time of confirmed pregnancy, women completed the state anxiety scale. At the end of six months, a second acceptability interview was administered.

Sample

Sixty persons admitted to a DI program were recruited; 58 agreed to take part. The mean age of the sample was 29.1 years, with a mean number of years married of 7.3 and a mean number of years trying to become pregnant of 4.5. A total of 20 women conceived by the end of six treatment cycles. Follow-up data were available for 35 women, 25 continuing in the program and 10 who were pregnant.

Comments

Reliability/validity/bias reduction not discussed.

Conclusions

Results showed generally positive initial attitudes toward DI. No systematic anxiety trends were identified, with no differences between women who became pregnant and those continuing in treatment. At follow-up, women acknowledged the strain involved in timing insemination to coincide with ovulation, with both pregnant and non-pregnant women attributing the outcome to their psychological and emotional state at the time. Improved methods of detecting the fertile period may help allay worries that insemination will not occur at the optimum time. Similarly, psychological preparation may help reduce doubts and anxieties over the availability of staff and engender realistic expectations about the likelihood of conceiving each cycle. A proportion of the sample believed that counselling would be beneficial.

Snowden, R., G.D. Mitchell, and E.M. Snowden. 1983. *Artificial Reproduction: A Social Investigation*. London: George Allen and Unwin.

Subject

To develop a social profile of the people who attended a single U.K. practice over 40 years and to determine how successful their use of DI had been. Secrecy associated with the DI use was examined in some detail. A series of recommendations are provided.

Methodology

The authors reviewed the literature dealing with DI, examined many DI cases (for demographic data), interviewed couples who were parents of DI children, and talked with older DI children and AI donors and practitioners. The study focussed on the social implications of DI and the frequently perceived need for secrecy. Interviews with parents of DI children were semi-structured (1.5-2 hours) and confidential. Subjects were patients who had attended a single practice over 40 years. Changes in demographic data over time also were examined.

Sample

The records of 986 couples were examined; of these, 899 had received DI only. A request for an interview was sent to a sample of 110 couples. A total of 74 were willing to be interviewed but only 67 interviews were completed. Non-manual workers (classified according to the husband's occupation) accounted for 52.4 percent. The husbands tended to be older than the wives. Almost 40 percent were married for more than five years.

Comments

It was noted that interview results were biased because some couples interviewed had continued a relationship with the practitioner for years after the birth of their children. Thus, they could be expected to have had a fairly positive DI experience. Reliability and validity not discussed.

Conclusions

Most couples were grateful for the availability of DI. Some were concerned that too little information was available in the early stages of infertility investigation, making it difficult for them to make fully considered decisions. Almost all expressed a belief that DI was preferable to adoption. The major preoccupation of most couples was to ensure that people outside the medical profession would not discover that they were receiving DI. In a subgroup of the sample (10 couples with DI children over age 18), it was found that most had told their children that they were conceived by DI, while most couples with younger children felt they would never tell their children. Recommendations for controlling the use of DI to minimize negative social impacts are included.

Soper, A.M. 1990. "The Life Crisis of Infertility and Its Impact on Women." Ed.D. dissertation, Boston University.

Subject

To examine whether infertility is a developmental crisis for women and to determine whether infertility had an impact on women's self-images, levels of ego maturity, careers, and relationships with family and friends.

Methodology

Potential subjects were contacted through RESOLVE. Comparison subjects were recruited using a networking technique. Instruments used included the Washington University Sentence Completion Test (WUSCT), a demographic questionnaire, and semi-structured interview questions. The WUSCT measured the subjects' ego stage levels, while 33 semi-structured interview questions were used to elicit information on the impact of infertility on self-image, relationships, and career or educational plans.

Sample

The sample comprised 18 women: 6 undergoing infertility treatment, 6 who had children after infertility treatment, and 6 who adopted children after treatment. All subjects were white, married, middle-class women of above-average education and income levels who lived in a large urban centre. Their ages were 30-44 years. An overview of the demographic data obtained is presented.

Comments

It was noted that item reliabilities for the WUSCT are somewhat lower than desirable; however, its construct validity has been demonstrated. More research is needed to illustrate its concurrent and external validity. Further discussion of the WUSCT is included. Other instruments were tested in a pilot study before beginning this research. Copies of questionnaires used are provided.

Conclusions

Subjects overwhelmingly reported that they felt as though their lives were on hold during infertility treatment, and infertility had negatively influenced their self-images and career plans. All reported that infertility had a major, sometimes stressful, impact on their relationships; however, they felt their marital relationships had become closer. The subjects who had children after infertility treatment reported that their lives were moving forward again and their self-images had become more positive. It was not found, however, that resolving the infertility crisis by becoming parents had resulted in higher levels of ego maturity, as measured by the WUSCT.

Stewart, S., and G. Glazer. 1986. "Expectations and Coping of Women Undergoing In Vitro Fertilization." *Maternal-Child Nursing Journal* 15: 103-13.

Subject

Descriptive data were gathered from interviews with three women who completed an IVF cycle at a large university hospital. Open-ended interview elicited information regarding each woman's IVF experience.

Methodology

This exploratory study involved interviewing the first three women to complete an IVF cycle at a large university hospital. Three open-ended questions were used: (1) How did the experience of IVF compare with what you expected? (2) What things helped you cope with the experience? and (3) What could have been done to help you more? The women's responses were to be used to design a longitudinal study to involve more subjects.

Sample

The three women were 29, 36, and 33 years old. Two were Roman Catholic and one was Methodist. Two women had family incomes between \$30 000 and \$50 000 and one had an income between \$10 000 and \$20 000. The women had been infertile five to ten years.

Comments

Reliability/validity/bias reduction not discussed.

Conclusions

A good description of each woman's responses to the questions is provided. All three referred to the up-and-down nature of the IVF experience. They found the uncertainty involved in the procedure difficult to tolerate. The two women who did not become pregnant classified the second half of the cycle, between ET and pregnancy test, the most difficult time. The woman who became pregnant found IVF's physical aspects more difficult than anticipated, and more difficult than the emotional aspects. All were happy with the care they received from the IVF team. Another common feature was their reliance on their husbands for support. In the authors' view, the IVF nurse can and should be instrumental in preparing patients for their IVF cycle, in supporting and comforting them throughout the cycle and afterward, and in promoting the spouses' physical and emotional involvement.

Takefman, J.E., et al. 1990. "Sexual and Emotional Adjustment of Couples Undergoing Infertility Investigation and the Effectiveness of Preparatory Information." *Journal of Psychosomatic Obstetrics and Gynaecology* 11: 275-90.

Subject

Exploratory study to evaluate the effectiveness of three types of preparatory information programs in reducing the sexual and emotional strains of the investigative process; to study specific psychological reactions to the infertility investigation; and to evaluate the power of psychological variables in differentiating favourable from unfavourable adaptation. The programs assessed took three forms: (1) emotional and sexual information; (2) emotional information; and (3) procedural information.

Methodology

Seven self-report questionnaires were used: the Marital Adjustment Scale, Derogatis Sexual Functioning Inventory, Eysenck Personality Inventory, STAI, Beck Depression Scale, Feelings About Infertility Questionnaire, and Fertility Information Questionnaire (developed for the study). Subjects underwent structured interviews upon entering the study and receiving a diagnosis, as well as monthly telephone interviews. They were randomly placed in three groups, each of which received different preparatory information regarding diagnostic tests. Results were statistically analyzed and compared.

Sample

The volunteer subjects consisted of 39 married couples commencing an infertility investigation. The women were experiencing primary infertility and the couples were unaware of its cause. All agreed to undergo five basic diagnostic tests. The women averaged 29.8 years of age; the men, 32.3 years. Of these, 39 percent of women and 52 percent of men worked in business or professions. Further demographic information is provided in tabular form.

Comments

For the unstandardized questionnaires (the Feelings About Infertility and Fertility Information questionnaires), pilot work ensured acceptable psychometric properties. Reliability/validity/bias reduction regarding the standardized questionnaires not discussed.

Conclusions

Results revealed that the group that received only descriptive information on the investigative procedure reacted more positively to the investigation than the groups that received additional information pertaining to possible emotional and sexual reactions. It was also

demonstrated that couples' baseline psychological profiles could be used to identify those at higher risk for poor adaptation to investigation. Further, baseline anxiety levels were found to be related to achievement of pregnancy at six months' follow-up. The findings suggest that infertility investigation has a negative impact on couples, which could in turn influence pregnancy outcome. Controlled studies should be carried out to identify effective stress-management programs for infertile couples.

Valentine, D.P. 1986. "Psychological Impact of Infertility: Identifying Issues and Needs." *Social Work in Health Care* 11 (4): 61-69.

Subject

The emotional impact of infertility on individuals and the marital relationship and implications for social work practice in such settings as fertility clinics, genetic counselling services, family planning centres, and other health and mental health facilities serving infertile persons.

Methodology

A semi-structured, focussed interview schedule explored the emotional impact of infertility on participants. Participation was voluntary and consisted of a 2-hour interview. Participants were asked to discuss: (1) feelings, conflicts, and sources of stress pertaining to infertility; and (2) methods used to cope with, resolve, or manage stress related to infertility. Interviews were audio-taped and dialogues transcribed for analysis.

Sample

Participants were solicited through media announcements and presentations. They were then asked to identify others who qualified for the study. The 26 participants represented 14 families. Their ages were 25-38 years. The mean age of the males was 33.1 years; the mean age of females was 31.8 years. Seventy-five percent held four-year college or graduate degrees. The mean length of infertility was 6.5 years.

Comments

A review of interview transcripts indicated an overall uniformity in format and content. The interview schedule is available from the author. It is noted that the results cannot be generalized given the homogeneity and small sample size and sampling method used.

Conclusions

Couples reported sadness, depression, anger, confusion, desperation, hurt, embarrassment, and humiliation. Behavioural reactions to infertility included disorganization, distractibility, exhaustion, moodiness, and obsessive thoughts and behaviours. Among the multiple stressors

described, medical procedures and personnel were described as insensitive and intrusive. The information obtained in fertility work-ups also added stress as past sexual behaviours and reproductive histories were uncovered. Results indicated that medical practices should be adopted that respond to the emotional needs of infertile people. Trained, skilled social work practitioners can meet these needs.

Wallace, L.M. 1985. "Psychological Adjustment to and Recovery from Laparoscopic Sterilization and Infertility Investigation." *Journal of Psychosomatic Research* 29: 507-18.

Subject

First, to establish the degree to which the reason for undergoing surgery accounts for the differences between individuals adjusting to and recovering from the operation. Second, to establish the perceived costs and benefits of laparoscopy. This is prerequisite to establishing which patients require special forms of psychological preparation.

Methodology

Patients were questioned over eight periods. Before admission, a structured interview was used to obtain medical, demographic, social, and household activity measures. Also used were a structured interview to obtain preferences for preparatory information; a 20-item comprehension test to assess understanding of information about hospitalization and surgery; measures of mood, including a six-item Worry Scale, Spielberger State Anxiety Inventory, POMS, and a measure of anxiety using the trait scale of the STAI. Follow-up measures included two questionnaires and the STAI and POMS measures.

Sample

The sample consisted of 131 patients undergoing laparoscopy (56 for sterilization, 50 for primary and 25 for secondary infertility investigation). Patients were demographically similar. Primary infertility patients were younger and had less surgical experience than other patients. At one week follow-up, 90 of 120 patients returned usable questionnaires. Eighty patients completed the six-week follow up.

Comments

No significant difference between patients who did and did not complete follow-up assessments in terms of psychological measures taken initially. It is unlikely, therefore, that any significant bias is present in the remaining sample. Reliability/validity not discussed.

Conclusions

The experience of laparoscopy was clearly stressful for all patients to some degree. The reason for laparoscopy did not seem to influence the amount of fear immediately before and after the operation, post-operative physical symptoms, or the majority of mood states at follow-up. There were significant differences between infertility and sterilization patients with respect to state anxiety on the morning of surgery, vital signs, post-operative intramuscular analgesia, and the speed of returning to normal activities. The investigation of attitudes toward the operation revealed that patients undergoing sterilization and infertility investigation were concerned about the costs and benefits of the operation, which include influencing not only fertility, but also menstruation and sexual activity. Patients misunderstood information about surgery, and the majority welcomed additional psychological preparation.

Williams, L.S. 1989. "No Relief Until the End: The Physical and Emotional Costs of In Vitro Fertilization." In *The Future of Human Reproduction*, ed. C. Overall. Toronto: Women's Press.

Subject

The reality of IVF as experienced by 20 Canadian women who participated in the author's Ph.D. research on parenthood motivation in couples seeking IVF.

Methodology

Descriptions are based upon interviews with 20 Canadian couples. Description of the women's IVF experience is broken into three parts: the period before hospital admission; the in-hospital period; and the two-week period following hospital discharge when a woman waits to learn if she is pregnant. Excerpts from discussions with women are provided to support the author's observations.

Sample

The sample consisted of 20 Canadian couples. Each woman had undergone at least one IVF attempt. A table shows the number of IVF attempts undergone and their outcome. All the attempts except one took place between 1983 and 1986.

Comments

Reliability/validity/bias reduction not discussed.

Conclusions

Most women found twice-daily hospital visits for Pergonal[®] injections, blood tests, and ultrasound scans tiring and stressful. Almost all experienced at least one side-effect from Clomid[®]/Pergonal[®], including

severe headaches and mood swings. A pervasive theme was the profound fear of being “cancelled” because their hormone levels were not rising or their egg follicles were not developing properly. Blood tests and ultrasound scans were perceived as tests that had to be passed to continue in the program. They described their hospital time before surgery as tense and emotionally charged but appreciated the support received from other women. Laparoscopy was much less stressful than the period leading up to it. The final stage of the process (waiting to be tested for pregnancy) was the most stressful. The author recommended further study into the physical and emotional safety of IVF.

2. Rank 2 Reviews

Description of Rank 2 Headings

A standardized form was completed for each Rank 2 study. Charts contained in this report specify the author(s), title, source, and year of publication of each article. A summary is provided, with information organized under the following headings:

- **Category**
Indicates style of article (i.e., editorial, review, prescriptive, analysis).
- **Summary**
Contains a brief review of the article, presenting author’s concerns, views, and findings as objectively as possible.

Space in each field was limited; however, an effort was made to include as much information as possible and to ensure that the summaries reflect the substance of each document reviewed.

Rank 2 Reviews

Achilles, R. 1990. “Desperately Seeking Babies: New Technologies of Hope and Despair.” In *Delivering Motherhood: Maternal Ideologies and Practices in the 19th and 20th Centuries*, ed. K. Arnup, A. Lévesque, and R.R. Pierson. London: Routledge.

Category
Analysis

Summary

Recent medical advances in the field of reproductive technology have irreversibly altered both the cultural meaning and the experience of motherhood. While numerous feminist thinkers are attempting to discern the defining features of modern motherhood, these very features are being radically transformed by the discovery, refinement, and promotion of new reproductive technologies ... Both female biology — those (once) seemingly immutable processes of conception and gestation — and the social and historical role of mothering take on new meaning in this context. (p. 284-85)

At least four social issues can be identified: 1) the further medicalization of the reproductive process, 2) the impact on family structure, 3) the commercialization of reproductive capacities, and 4) the potential eugenic uses of artificial reproduction technologies. (p. 298)

Social policy already lags far behind these rapidly developing medical advances. As the technologies become more sophisticated, the social dilemmas posed by them become more complex. The question is who is going to control these technologies and under what conditions? (p. 304)

As with any new social process or technology, we are granted an opportunity to rethink and reorganize some of our most deeply embedded assumptions ... This potential can be lost, however, if we allow the use of these technologies to be divorced from a thorough and open discussion of the social context and consequences of reproduction and mothering. Isolated and unquestioned, they may only serve to reinforce and exacerbate the traditional hopes and despairs of women as childbearers. As the limits of the possible change, so must our understanding of choice and the desirable. (p. 304-305)

Andrews, L.B. 1986. "Legal and Ethical Aspects of New Reproductive Technologies." *Clinical Obstetrics and Gynecology* 29: 190-204.

Category

Prescriptive

Summary

Presenting guidelines for a moral assessment of new reproductive technologies, the author recommends:

The reproductive technology should not create serious harm to the other participants in the process; ... [should] not be unduly risky for the adults involved in the process ... The potential harms include assaults to autonomy, physical risks, and psychological risks. (p. 191-92)

The application of the new reproductive technologies should not be unduly psychologically harmful to society. (p. 192)

Any law governing alternative reproduction implicates a fundamental legal and moral right, the right to procreate. In such a sensitive area, regulation should be put into place only when the need for it is clear. With that in mind, laws should be adopted clarifying the paternity of the children conceived through alternative procreation. Laws should also be adopted to monitor the outcomes of the procedures and to guard against known harmful effects of the procedures by mandating screening and requiring recordkeeping. To determine the appropriate legal regulation, a medical model should be followed. Applications of the new reproductive technologies should be allowed unless evidence convincingly indicates they would unduly harm the participants or society. (p. 201)

Baruch, E.H. 1988. "A Womb of His Own." In *Embryos, Ethics, and Women's Rights: Exploring the New Reproductive Technologies*, ed. E.H. Baruch, A.F. D'Adamo, Jr., and J. Seager. New York: Harrington Park Press.

Category

Editorial

Summary

Although some feminists formerly saw utopian possibilities in reproductive technology, many now fear that the new technologies are turning women's bodies into test tubes. They feel that these technologies are designed less to help infertile women than to appease men's envy of women's reproductive power. The consequences of the new technologies for the psychology of women and children and the future creation of culture are open questions. Should the technologies succeed in taking reproduction out of the body altogether, it remains to be seen whether women will gain in freedom, or whether this will simply fulfill the age-old misogynistic fantasy of depriving women of their central place in procreation. (p. 135)

This author is concerned that now that reproduction is *ex utero*, women may need to fight to have children in the natural way:

Control over one's own body is perhaps the central feminist credo. It is what is now feared will be lost through the new reproductive technology. It was perhaps inevitable in our technological age that conception, the last of the cottage industries, would be taken out of the home and placed in the antiseptic factory of the lab. (p. 136)

To push the plot lines further, some day it may be possible for a child to have no mother at all, that is, for reproduction to take place completely outside the body. (p. 137)

It is a common belief among feminists now that the new technology with its IVF and embryo transfer was designed less to help the infertile than to appease men's envy of women's reproductive power. Once again,

womb envy, as Karen Horney calls it, rears its ugly head. It is no small surprise to find that on the issue of reproductive technology, some radical feminists sound more like the women of the New Right than anyone else. They too fear men's intrusion into motherhood, the *sanctum sanctorum*. (p. 138)

Batterman, R. 1985. "A Comprehensive Approach to Treating Infertility." *Health and Social Work* 10 (1): 46-54.

Category
Analysis

Summary

Drawing on clinical experience in counselling infertile individuals and couples and leading support groups for such clients, the author analyzes this life crisis in terms of emotional stages experienced by the individual and defines the therapeutic role of the social worker in guiding clients through the tasks of resolution. This article examines the treatment of the psychological dimensions of infertility and the social worker's role in the assessment and treatment of infertile couples.

Its material stems from published literature and the author's experiences leading groups and treating infertile individuals and couples at the Jewish Family and Child Service in Portland, Oregon. These individuals are white, middle-class men and women with mixed ethnic and religious backgrounds.

Infertility has become a condition that often necessitates social work intervention. (p. 46)

The emotional states infertile people experience in accepting the loss of their fertility are similar to the stages in dying described by Kübler-Ross. Individuals react differently to infertility, depending on their personality structure, the meaning they attach to having children, and their coping mechanisms. Their feelings vary in duration and intensity and are not clearly delineated as people move from one state to another. (p. 47)

The stages are surprise or shock, denial, anger, and isolation. Guilt feelings may be strong and confusing.

As infertile persons no longer deny their infertility, as they decide to undergo surgical procedures and various drug therapies, and as they are faced with time passing without their having succeeded vis-à-vis pregnancy, they begin to feel a grave sense of loss and sadness. (p. 48)

These emotions can have an impact on individuals' self images "in varying intensities and [elicit] different coping styles, from healthy to maladaptive." (p. 49)

For all infertile clients, the goal of experiencing and articulating the emotional phases of infertility is important for the completion of the first task of resolution. (p. 50)

The social worker's role in that resolution is discussed.

Beck, W.W., Jr. 1976. "A Critical Look at the Legal, Ethical, and Technical Aspects of Artificial Insemination." *Fertility and Sterility* 27: 1-8.

Category

Editorial

Summary

This article explores the legal, ethical, and technical aspects of AI.

Because of its unnatural character in conception, artificial donor insemination raises issues that must be realized by both the physician and the infertile couple ... it is incumbent on the physician performing AI to counsel the couple on the various legal and ethical aspects of the subject. The couple is often worried and anxious. Individually and together they must be satisfied and confident about what they are doing ... unanswered questions, fears, and doubts can contribute to an irregular or absent ovulatory phase in the woman; this makes the timing of the insemination difficult if not impossible. The proper preparation and counseling of the couple and their subsequent peace of mind go a long way in creating a climate that is favorable for success with AID. (p. 7)

Bell, J.S. 1983. "Psychological Aspects." In *Male Infertility*, ed. T.B. Hargreave. New York: Springer-Verlag.

Category

Review

Summary

This article reviews the research on psychological factors, such as psychogenic infertility, infertility management, investigation and treatment, results of investigations, and the termination of treatment. Bell concludes that:

...psychological factors and their appropriate clinical management must be considered for all patients throughout investigation and treatment, and not only when organic factors have been excluded or treatment terminated. There is evidence that some problems could be avoided or attenuated by this approach. Nevertheless, infertility counselling has

historically been concerned mainly with those couples for whom treatment has proved unsuccessful, and it is indeed important to assess what can be accomplished for this group. The success of the clinic should be judged by its ability to maximize the quality of life of all its patients, not only by the pregnancy rate achieved. (p. 52)

Although it seems that the concept of psychogenic infertility may have a rather more limited application than once was thought, and although much basic research remains to be carried out, there can be no doubt that psychological factors must routinely be taken into account in the management of the infertile couple. (p. 53)

Berger, D.M. 1977. "The Role of the Psychiatrist in a Reproductive Biology Clinic." *Fertility and Sterility* 28: 141-45.

Category

Prescriptive

Summary

This paper discusses various issues that confront the psychiatrist consulting in a reproductive biology unit. It makes the following recommendations for such a unit:

- (1) An *initial* interview to deal with anxiety, to discuss frankly what might be expected during the infertility work-up, and to explore sexual and marital problems, concerns, and unrealistic beliefs, should involve *both* partners...
- (2) Circumstances that, in the opinion of the team, merit special attention from a psychiatric viewpoint should involve a *routine* psychiatric referral. In our clinic a routine investigation is prescribed (1) for all couples considered for artificial insemination by a donor, to assess the couple's motivation, the stability of the marriage, and the capacity for parenthood, and to discuss some of the legal difficulties; and (2) after the infertility work-up for every so-called physically "normal couple."
- (3) Because marital problems often become manifest during an infertility work-up, every reproductive biology unit should have available a facility that deals with such problems both with short-term supportive and behaviorally oriented techniques and with more intensive therapies.
- (4) *Every* staff member of a reproductive biology unit should become involved and familiar with psychologic, ethical, and legal issues pertaining to infertility...

- (5) After completion of the work-up, couples should be encouraged to feel free to consult with the nurse, social worker, or psychiatrist at a later date, if they so wish, in regard to psychologic problems. (p. 145)

Berger, D.M. 1982. "Psychological Aspects of Donor Insemination." *International Journal of Psychiatry in Medicine* 12: 49-57.

Category

Review

Summary

This paper provides an overview and critique of studies dealing with psychological issues pertinent to DI. The critique paid particular attention to the concealment that surrounds DI.

Studies of couples beforehand do not arrive at criteria for choosing psychologically suitable couples. Follow-up questionnaires are superficial and cannot inform us which couples and what percentage of couples encounter psychological difficulties. Case reports of couples who encountered difficulties are too few to permit generalization and cannot specify AID's role in generating symptoms. A second look at the data suggests that, although overlooked, the secrecy surrounding AID may create psychological difficulties, a view supported by the findings at our clinic. A plea is made with specific recommendations to create an ambience in which openness is possible, and which will allow in-depth research of the psychological aspects of AID. (p. 49)

Blackwell, R.E., et al. 1987. "Are We Exploiting the Infertile Couple?" *Fertility and Sterility* 48: 735-39.

Category

Editorial

Summary

This article by 11 experienced practitioners in the fields of reproductive endocrinology and infertility express their concern about exploitation of the infertile couple.

Their concerns focus on:

- (1) the malpractice crisis, which is forcing obstetricians into the subspecialty areas of gynecology without adequate training; (2) the development of new technology, which often occurs in an ethical and

regulatory vacuum; and (3) the entrance of for-profit organizations into the infertility arena. (p. 735)

Bombardieri, M.A., and D. Clapp. 1984. "Easing Stress for IVF Patients and Staff." *Contemporary Obstetrics and Gynecology* 24: 91-97.

Category

Prescriptive

Summary

This article deals with how an IVF clinic team can best provide support and help in decision making concerning IVF. The authors, a clinical social worker and medical information officer, suggest the following five-step decision-making process: (1) taking stock — assessing the direction toward which each partner is leaning; (2) gathering information; (3) preparing psychologically; (4) making the final decision; and (5) implementing the decision.

The authors also suggest that the IVF team may need a support system as "it is difficult to work with such tense patients and to witness a significant number of failures." (p. 96)

Bryant, H. 1990. "The Infertility Dilemma: Reproductive Technologies and Prevention." Ottawa: Canadian Advisory Council on the Status of Women.

Category

Analysis

Summary

This paper provides an overview of the impact of new reproductive technologies which are designed to treat infertility. It explores the development of preventive approaches to infertility. The author outlines research needed and changes in social policy to shift emphasis "from cure to cause." The author believes there should be a shift from infertility as a medical problem to a "reproductive health concern which requires societal consideration and input from many disciplines." (p. iii)

Many of the new technologies used to treat infertility are, in fact, experimental. (p. 7)

The problem with NRTs as research techniques may not be that such research is occurring, but that current research is not being carried out in a definitive way to ensure the effectiveness of these technologies. To prove effectiveness, it must be demonstrated that treated couples were

more likely than untreated or alternatively treated couples to bear living, healthy children, without developing other physical or psychological side effects, over a reasonable period of time. (p. 8)

Bryant outlines the low success rates of DI, AI with husband's sperm, IVF-ET, and GIFT, observing that media and clinics often place more emphasis on the number of pregnancies rather than live birth rates. The exaggeration by sometimes uncontrolled studies offers some hope to infertile couples; however, "...infertile couples who believe the new technologies offer new hope may enter a program with expectations that exceed the reality." (p. 13)

Although the treatment of infertility is a medical and technological challenge, many of the causes and most of the consequences of infertility are not medical, but social. Thus any considerations of the new reproductive technologies must emphasize the personal and social aspects, along with the biological ones. (p. 26)

Bryant recommends that the biological suitability of a couple is a medical decision, whereas the other criteria, such as the suitability of the marital relationship, is made by a multidisciplinary team (ethical, sociological, etc.) not only clinic health professionals. If infertility research and therapy are to be publicly funded, then the public should have equal access. Counselling facilities that explore alternatives should be available to couples, with support groups for those who do not conceive and exit counselling for those who wish to cease therapy. The social/medical milieu must foster the attitude that women have the right to control their own sexuality.

Cabau, A., and M. de Senarclens. 1986. "Psychological Aspects of Infertility." In *Infertility: Male and Female*, ed. V. Insler and B. Lunenfeld. Edinburgh: Churchill Livingstone.

Category

Editorial

Summary

This article discusses the psychological aspects of infertility using various research findings. Of particular interest is the topic "Healing the Patient or Curing Infertility?" This section considers the meaning of the inherent doctor-patient relationship. The authors stated:

When confronted with a situation of infertility, three human dimensions must be explored:

1. The attitudes or emotions of the women, or of the couple;

2. The counter-attitude and feelings of the doctor, which will determine the approach;
3. The psychological climate which corresponds to the varied and changing interactions which take place between the doctor and the patient. (p. 667)

Chatel, A. 1983. "Aspects psychologiques." In *L'insémination artificielle thérapeutique*, ed. M.J. Melançon. Quebec: Presses de l'Université Laval.

Category

Editorial

Summary

This author reviewed the literature and experiences of participants at an infertility clinic in Montreal, Quebec. She found that, in an age of instant gratification, prolonged, unresolved infertility causes uncertainty and self-doubt. Some men equate the ability to procreate with masculinity and power. Some view infertility as a severe blow to themselves as persons, losing interest in sex or other activities. Others compensate by becoming involved in other areas of living. Some fear abandonment by their fertile partners. DI can allow women to experience pregnancy. Adoption is a slow process, and some fear that the natural mother may reclaim the child.

The role of the doctor in IVF goes beyond the medical procedure. He/she permits the impregnation to go forward, the symbolic power of which should not be underestimated.

The decline in religiosity in Quebec contributes to the marginal concern among couples over the moral and religious aspects of this procedure. Legal concerns over custody in case of separation or the "natural rights" of the sperm donor cause a greater level of concern.

Interviews were conducted with couples preparing for IVF to help ease their fears and uncertainties. Generally, couples who reject adoption, if free of other constraints, may be unable to surrender the wish to bear a child.

The definition of the true father as the sperm donor or as the caregiver in couples' minds is important. New reproductive technologies force the redefinition of words governing family relationships. Donors who resemble the father are used, but there can be no guarantee against hereditary imperfections.

Most couples prefer to keep IVF a secret. The motivations for this may relate to a failure to accept the "death" of fertility. Issues of social acceptance or family pride may be involved. The issue of secrecy is fraught with much that may do psychological harm to the couple or, eventually, to the child.

The uses of IVF raise some difficult social and moral issues. It may lead to eugenic control of breeding, modify family structures, change relations between the sexes, and challenge such institutions as marriage.

The author states that (in 1983) IVF was a therapeutic solution to a couple's infertility when the problem is attributable to the man. The determining psychological factors governing access are: (1) a stable heterosexual home life; (2) an absence of severe psychological pathology, including limited mental capacities; and (3) the agreement of both partners to proceed.

Few scientific studies have been done on the psychosocial impact on couples or resulting children.

Christie, G.L., and M.E. Pawson. 1987. "The Psychological and Social Management of the Infertile Couple." In *The Infertile Couple*. 2d ed., R.J. Pepperell, B. Hudson, and C. Wood. Edinburgh: Churchill Livingstone.

Category

Prescriptive

Summary

We are only just beginning to grasp the complexity of the relationship between psyche and neuroendocrinology (Seibel and Taymor 1982), and to recognize that there are many avenues through which it is possible for emotions to disturb the sensitive and subtle regulation of reproduction. (p. 313)

As always in medicine, the physician must acquire an holistic perspective on infertility, so that the social, psychological and somatic factors can be assessed in each diagnostic work-up. Many couples will also require emotional support and counselling during treatment, especially when our investigative and treatment techniques intrude deeply upon the marital relationship, separating loving sex from reproduction. (p. 313)

We believe that the responsibilities of the treating physician include the need to ensure, as far as is possible, that the whole treatment process is a learning and growth-promoting experience for the couple. A healthy adaptation to the outcome of treatment (whether a baby or a verdict of infertility) is at least as important as the outcome itself. We also believe that the early interviews with the couple are of fundamental importance in this regard, not only because they uncover problems of the highest priority (whether external family problems, marital maladjustment, sexual dysfunction or covert conflict over the prospect of parenthood) but also because of their significance in the developing relationship between the couple and the physician. (p. 330-31)

The treating physician must be able to respond to patients with empathy and understanding. A sensitive and educated ear is required to assess the deeper feelings and motivations in each partner ... The magnitude of influence may be enhanced by positive transference in the psychoanalytical sense, for example the woman may endow her physician with attributes determined by unconscious wishes directed towards an ideal father (or mother) image ... However both positive and negative transference, if too intense, may interfere - for example the woman who responds to AID with anovulatory cycles because of the increasing significance of the physician as an incestuously-desired parent-figure or a feared judgemental one. (p. 331)

Sound medical management of the infertile couple requires that we assess the couple carefully, in body, mind, and 'soul', so that we do not either under-treat, or over-treat, them. And we need to remember that a mature adaptation to the outcome of treatment (whether this is a baby or a verdict of infertility) is at least as important as the outcome itself. Nijs and Rouffa (1975) suggest that two things can be asked of the treating physician. Firstly, he must be able to transcend the medical model, acquire a relationship perspective on the couple and view their problem in its psychosocial setting. In this he may well be aided by the psychoanalytically trained psychiatrist or psychologist. But he also needs to be able to transcend the psychoanalytic model, as this can tend to obscure psychosocial realities behind the drama of an individual's uncovered fantasies. (p. 337)

Clément, J.-L. 1983. "L'entretien psychologique des couples avant l'insémination artificielle avec donneur." In *Aspects psychologiques de l'insémination artificielle*, ed. C. Manuel and J.-C. Czyba. Villeurbanne (France): Simep.

Category

Prescriptive

Summary

The author writes about the role of psychological counselling in a French IVF program. The psychological interview is not intended to distinguish between couples who should or should not have children but to help make the artificial part of the process seem natural for the couple. Clément found that a number of fears arise out of the IVF treatment. For the donor, there is the fear that his natural children might marry his IVF progeny. For the woman, there is the fear the husband might reject the child that is not of his body, or that the child might be deformed or obviously of another race. That sperm is processed and frozen heightens

these concerns. The author concludes that the psychological interview before IVF can be used to calm the couple's fears, dispose of their fantasies, and affirm them in their course.

Daniels, K.R. 1986. "New Birth Technologies: A Social Work Approach to Researching the Psychosocial Factors." *Social Work in Health Care* 11 (4): 49-60.

Category

Review

Summary

This article describes a social work approach to researching the psychosocial factors associated with the rapid developments in the new reproductive technologies field in New Zealand and the role of social workers as part of the clinical team. Daniels believes the issues associated with research in this field are: recognizing who is in control and where the power resides; setting up a program so that doctors are worked with rather than against; moving into research from a firmly established and respected clinical involvement; clarifying research aims and methodology; reaching agreement/understanding about the management of information obtained; using social work skills; and obtaining project endorsement from appropriate ethics committees.

Dennerstein, L., and C. Morse. 1988. "A Review of Psychological and Social Aspects of In Vitro Fertilisation." *Journal of Psychosomatic Obstetrics and Gynaecology* 9: 159-70.

Category

Analysis

Summary

The role of psychological factors in infertility is complex. Psychological issues intertwine with the physical, often with additive effects. The very diagnosis of infertility is likely to cause stress. In addition, the many investigations and procedures compound distress. There is probably a small number of patients in whom psychological factors may exacerbate infertility and influence the patient's and partner's response. Mental, sexual, marital and social adjustment may all be affected. The procedure of IVF is likely to have a further impact.

The clinician is advised to incorporate consideration of the psychological aspects of infertility into every aspect of the investigation and treatment

programme. The addition of a psychosocial team may assist the gynaecologist in this and help the couple to make an optimal adjustment. (p. 168)

Edelmann, R.J. 1989. "Psychological Aspects of Artificial Insemination by Donor." *Journal of Psychosomatic Obstetrics and Gynaecology* 10: 3-13.

Category

Review

Summary

This paper reviews current knowledge and future research needs regarding the psychological factors involved in DI. Four areas are considered: (1) the psychological characteristics of couples selected for DI; (2) the impact of DI on the couples concerned; (3) the psychological impact of DI on the child; and (4) the counselling needs of DI couples.

Edelmann concludes:

Much of this research has produced inconclusive results and half-answers and allows for only tentative conclusions to be drawn. Certainly there is a clear need for further carefully conducted studies directed towards key areas. Whether AID should be restricted to certain couples is obviously a major dilemma. It is clear however that assistance should be available to couples in order to help them arrive at the "correct" decision; in this way couples may effectively screen themselves. Counselling for AID couples can thus be provided both to facilitate the couple's decision concerning AID and to facilitate the different coping strategies required, dependent upon successful or unsuccessful outcome in terms of conception. While some research has addressed the former issue there has been little consideration of couples' needs following AID, and clearly this issue needs to be addressed.

Certainly the effects of the AID program on the couples concerned are not clearly understood. Further research is required to investigate points of stress within the AID procedure for the female concerned; the lack of anxiety reported by the women in the one study in this area needs to be looked at in further studies. Of equal importance is the need to investigate the male's adaptation to an AID child in the family ... and to monitor possible effects of this upon the family. The latter can only be achieved by carefully conducted longitudinal studies, which is a difficult matter given the secrecy associated with AID. Ideally we need to know more about possible deleterious effects of both providing selected information and maintaining secrecy, upon the child and the family. Ultimately we need to gain the co-operation of families involved

in AID in order to investigate as sensitively as possible the effects on the family concerned. (p. 10-11)

Eichler, M. 1989. "Reflections on Motherhood, Apple Pie, the New Reproductive Technologies and the Role of Sociologists in Society." *Society-Société* 13 (February): 1-5.

Category

Editorial

Summary

This article raises some questions about the use of new reproductive technologies as they pertain to "motherhood" and the societal role of sociologists. Some of the author's questions are: What are the long-term consequences of having undergone intensive, unsuccessful infertility treatment? What are the long-term effects of heroic efforts on mothers, fathers, and children in successful treatments? What is the effect of preconception contracts for the production of children? What are the effects of anonymity of genetic parentage on offspring and on recipients (and their spouses, where applicable)? What are the selection criteria for admission to various treatment programs employed by private clinics and hospitals? What information is conveyed to clients? What are the consequences of "donating" an egg on a donor (or vendor) and other affected parties? What types of women volunteer their eggs (if they do so) and why? What types of men volunteer their semen (if they do so) and why? Most important, what are the reasons for infertility? How much of it could be prevented?

Gavarini, L. 1989. "La stérilité: un problème socialement construit avec la procréation médicalement assistée." In *L'avenir-santé au féminin*, ed. C. Gendron and M. Beauregard. Boucherville: Gaëtan Morin.

Category

Editorial

Summary

This writer claims that a state of emergency has been declared, that there is an epidemic of sterility, without yet being able to make serious studies of the extent of the problem and its development. When objections are raised to medically assisted procreation on the grounds of cost, both psychological and financial, they are put aside in the name of women's wishes and consent. The writer believes these techniques become a

panacea, granting all women the right to bear children. He says that France is setting up (1989) a vast network of fertility centres, almost as many as in the United States, without knowing: (1) how the level of needs was determined; (2) how many patients will be treated at each centre; or (3) what definition of sterility will be used to determine the level of need for the service.

Greenfeld, D., and F. Haseltine. 1986. "Candidate Selection and Psychosocial Considerations of In-Vitro Fertilization Procedures." *Clinical Obstetrics and Gynecology* 29: 119-26.

Category Analysis

Summary

The psychological impact of the new reproductive technology should not be understated. The history of infertility treatment and failure to achieve pregnancy that most couples bring to the program, along with their hopes and expectations for success, makes them extremely vulnerable to anxiety, unrealistic expectations, and grief reactions...

Physicians who work with IVF patients do realize that the procedure is stressful. Often the stress is viewed as primarily the patients', and we are asked to study the level of stress ... the stress is perceived because the physicians and staff are also under stress ... Failure of a cycle is felt not only by patients but by the medical team and the laboratory team ... Studies on the effects of IVF on the participants other than the couples will be done, and papers on "burnout" of staff and physicians will be written.

Centers with small groups of patients will have very few successes, and only large programs with 10-20 patients a week will have enough pregnancies to monitor for the continuous positive reinforcement of the staff that is necessary for their morale ... Newer knowledge will permit better monitoring of an IVF cycle, and patients will have more accurate information about their chances in each cycle. This should assure the patients of more privacy and give them back some control over their reproductive capacities. (p. 125)

Greenfeld, D., et al. 1986. "Infertility and the New Reproductive Technology: A Role for Social Work." *Social Work in Health Care* 12 (2): 71-81.

Category
Analysis

Summary

Infertility affects 1 in 6 couples in the United States during their childbearing years. The causes are sociological, medical and environmental. The new reproductive technology such as in-vitro fertilization and the alternatives to biological parenting such as surrogate motherhood raise legal and ethical issues as they raise the hopes of those couples previously unable to have a baby. As expectations have risen and treatment options become more complex, the social worker has become an essential member of the treatment team. (p. 71)

This article is written with social workers in mind, detailing descriptions of infertility and its causes, treatment, and psychological impact, to establish a background for social workers seeing infertile couples.

A clear understanding of each of these areas is essential to fulfill the role of the social worker in such a setting. This role includes, but is not limited to, functions as counselor and educator. (p. 72)

Hornstein, F. 1984. "Children By Donor Insemination: A New Choice for Lesbians." In *Test-Tube Women: What Future for Motherhood?*, ed. R. Arditti, R.D. Klein, and S. Minden. London: Pandora Press.

Category
Editorial

Summary

In spite of the many difficulties involved in making any kind of far-reaching change, donor insemination has been an enormously exciting step in breaking through the constraints placed on women by sexist prohibitions. It has opened the door for allowing women to arrange their lives in a way that best suits their needs. For lesbians and some heterosexual women, donor insemination represents a new reproductive choice — one which can remain in our control. (p. 373)

The intention on the part of feminist health services who provide donor insemination is less a desire to branch out into additional services but rather a strong political statement in support of a woman's right to make

her own reproductive decisions. The feminist clinics find themselves in the unique position of having physicians on staff who have access to commercial sperm banks and want to make the resource available to the community. But they are adamant about their belief that physicians should not make decisions for women about whether or not they will have children. (p. 377)

There needs to be continuous support for mothers and for the rights of non-biological mothers who are part of the children's lives. We need to recognize the rights of the donors. But in the midst of trying to carve out new ways of doing things in an ethical way, we should also take joy in the fact that we have broken new ground. We have created new and important life choices for many people. We have taken back a little more of what is rightly ours — the chance to make decisions about how we will live our lives. (p. 379)

Hubbard, R. 1980. "Test-Tube Babies: Solution or Problem." *Technology Review* 82 (March/April): 10-12.

Category

Editorial

Summary

The author is a biology professor at Harvard University and is co-editor of *Women Look at Biology Looking at Women* (Cambridge: Schenkman, 1979).

The push toward this technology [IVF] reinforces the view, all too prevalent in our society, that women's lives are unfulfilled, or indeed worthless, unless we bear children. I understand the wish to have children, though I also know many people — women and men — who lead happy and fulfilled lives without them. But even if one urgently wants a child, why must it be biologically one's own? ... Why not try to change the American and international practices that make it difficult for people who want children to be brought together with children who need parents? ...

But I would argue that to promise children to women by means of an untested technology — that is being tested only as it is used on them and their babies — is adding yet another wrong to the burdens of our socialization. IVF is expensive and unnecessary in comparison with many pressing social needs, including those of children who need homes. We must find better and less risky solutions for women who want to parent but cannot bear children of their own. (p. 12)

Kaplan, I.J. 1989. "Psychological Aspects of Infertility and the Assisted Reproductive Technologies." Psy.D. dissertation, Hahnemann University Graduate School.

Category
Analysis

Summary

This dissertation addresses the psychological aspects of infertility and the assisted reproductive technologies. The document contains a brief historical overview and description of infertility. It addresses the role of psychological factors in the etiology of infertility. The reaction to infertility is described as a biopsychological crisis with a chronological presentation of stages: initial phase (shock, surprise, denial); reactive phase (prolonged, two years or more; frustration, anger, anxiety, guilt, depression, and isolation); and final phase (resolution and future planning).

Kaplan investigates the psychological meaning of infertility from a theoretical standpoint using the psychoanalytical/sociological writing of Chodorow (1978), who explains the mechanisms of the psychological reproduction of mothering by women in our society. By extension, the theory is applied to infertility to account for the differences in intensity between men's and women's reactions to infertility. She concludes that the experience appears to be more painful and difficult for women to accept. The document discusses the psychological aspects that accompany the physical experiences of diagnostic tests and their meaning. Various treatments are described, with a focus on the emotional responses to assisted reproductive technologies. Stress associated with failed treatment cycles and unresolved infertility is highlighted. Finally, the author considers the role of the psychologist, including therapist and educator, and advocates a more holistic and humane medical approach to infertility and its treatment.

Klein, R.D. 1984. "Doing It Ourselves: Self Insemination." In *Test-Tube Women: What Future for Motherhood?*, ed. R. Arditti, R.D. Klein, and S. Minden. London: Pandora Press.

Category
Editorial

Summary

Klein describes a self-insemination program that functions without the interference of a man as sexual partner or medical adviser. Women in these groups see the experience as a liberating new approach to the concept of parenting, in which the conventional "one child-one mother" relationship is exchanged for a close inter-relationship of a group of mothers and their children. (p. 382)

Klein, R.D., ed. 1989. *Infertility: Women Speak Out About Their Experiences of Reproductive Medicine*. London: Pandora Press.

Category

Review

Summary

This 288-page book collects writings by women about their experiences with reproductive medicine. The sections are entitled: Infertility Treatments; Experiencing IVF; Exploiting Fertile Women in the Name of Infertility; Rethinking In-Fertility: Establishing Positive Frameworks; and Resistance: From the Exploitation of Infertility to an Exploration of In-Fertility by the Editor. Included are an extensive glossary, notes on contributors, a resource list, and suggestions for further readings.

Koch, L., and J. Morgall. 1987. "Towards a Feminist Assessment of Reproductive Technology." *Acta Sociologica* 30: 173-91.

Category

Editorial

Summary

The authors come from international arenas: Koch is with the Institute of General Medicine in Copenhagen, Denmark; Morgall is with the World Health Organization, Programme for Appropriate Health Care Technology, Copenhagen.

They state that the feminist literature deals only briefly with issues of technology assessment.

A feminist oriented assessment of this [IVF] as well as of all other reproductive technologies is needed because IVF deals directly with the female body; via the female body, IVF and other reproductive technologies change the social relations between the sexes; they change

the concepts of maternity and paternity, and they are the key to the age of genetic engineering of the human body and human race. (p. 173)

They highlight problems now being debated:

Ethical/legal questions: When does an embryo become a person? Who owns and controls an embryo in human experimentation? Who owns and controls an embryo produced in a glass dish? If an embryo is frozen and the parents die, what is to be done with it?

Social implications: There is well-founded fear that normal fertilization might be replaced by IVF with gene therapy, thus eliminating genetic diseases.

Social roles/social conceptions: Who should select consumers? What are the criteria for qualifying and who decides? What or who is a parent? The woman who bears the child? The woman who donates the ovum? What about natural and social fathers?

Economic issues: The cost of this technology to the public and private sectors is tremendous. Sperm/ova and embryos/children have a commercial potential.

The history of technology assessment methods (controlled clinical trials, synthesis methods) is reviewed generally, and then methods used in Denmark are presented. Regarding the method used in Denmark, the authors have reservations:

... because technologies are not merely tools, but a complex structure of tools, techniques, organizations and supportive systems, the introduction of a new technology has implications for the social and power structure of any society ...

It seems obvious that if the introduction and assessment of new technology in Denmark is to bear the "imprint" of a democratic society, conflicting interests should be allowed to find their way into technology assessment. For this reason we shall in the following, base our presentations on a conflict-oriented understanding of new technology, and, since this is an attempt to do feminist technology assessment, to look for possible sex-related differences of interests. (p. 179)

Women's studies have criticized both the fields of medicine and technology separately and together. The critique in medicine can be divided roughly into the following four categories:

1. *medicalization of the female body.* This includes issues of defining normal *bodily* functions (such as menstruation, pregnancy, birth and menopause) and *social* issues (such as rape and violence) as medical problems requiring *medical* solutions;
2. *male-dominated medical hierarchy.* This includes women's position in the medical hierarchy where the *minority* of men are in the decision-making positions (physicians) and where women who are the *majority* of health workers (nurses, nurses helpers, home visitors, etc.) are in the lower ranks with little decision-making power;

3. *medical authority.* Within the past 100 years the medical profession has gained much prestige, power and therefore authority (often this authority is compared to that which the clergy had previously in Western culture). Historically, as well as today, the field of medicine is one of the most important ideological forces in society because it defines what "a normal woman" is; and

4. *women as providers of health care.* This includes the "invisibility" of women as traditional providers of "unpaid" health care as well as the working conditions and occupational health issues of "paid" female health workers. (p. 179-80)

... we have shown the need for a women-specific assessment of new reproductive technology. We have illustrated the limitations of a number of methods and pointed to the advantages of a need-oriented approach. We have ascertained that an ethics debate must include sex-related differences and criteria. Issues to be included in a women-specific model of technological assessment and to which such a model should be sensitive range from technical/medical to social/legal and cultural, indicating that a feminist technology assessment cannot limit itself to a strict assessment of technology but must view technology in a social context of conflicting interests.

We must conclude that a woman's view in assessing reproductive technology is essential for four basic reasons:

1. women's bodies are the immediate objects of intervention;
2. the introduction and expansion of new reproductive technology will change the social relations of the sexes in a direction that may be detrimental to women's position in society and the family;
3. the new reproductive technologies will fundamentally change the concepts of maternity and paternity, as well as social and cultural structures surrounding women's lives and bodies; and
4. as new reproductive technologies are the key to the age of genetic engineering of the human body and the human race, an assessment including women's social and cultural experiences is vital for future decisions in this area.

Remembering that the first appeal for a thorough assessment of medical technology was from a woman, we call for an increased effort to develop methods and theories in the new discipline of feminist technology assessment based on the interests and experiences of women. (p. 189-90)

Leader, A., P.J. Taylor, and J. Daniluk. 1984. "Infertility: Clinical and Psychological Aspects." *Psychiatric Annals* 14: 461-67.

Category

Editorial

Summary

These authors from the University of Calgary infertility clinic are interested in the counselling of infertile couples and make the following point:

While very little systematic research has been devoted to determining the specific psychological needs of the infertile, or the effectiveness of current assistance in alleviating the emotional difficulties experienced by them, the available research does support the need for an interdisciplinary approach to the management of infertile couples. Both medical and psychological assistance may need to be provided within a supportive, non-judgmental, empathetic and caring milieu, which helps the man and woman to come to terms with their infertility. (p. 466)

Such efforts may be necessary at one or at all stages of the infertility experience. Further research on the psychological impact of infertility and the most appropriate way of treating problems that arise from infertility are necessary. The increasing complexity of infertility assessment techniques and treatments makes this need urgent. (p. 467)

For those working with infertile couples, familiarity with the available literature is necessary if the health care personnel is to begin meeting the needs of this group of patients. (p. 461)

Lorber, J. 1988. "In Vitro Fertilization and Gender Politics." In *Embryos, Ethics, and Women's Rights: Exploring the New Reproductive Technologies*, ed. E.H. Baruch, A.F. D'Adamo, Jr., and J. Seager. New York: Harrington Park Press.

Category

Review

Summary

From the point of view of the couple rather than the individual, infertility is in many ways a social rather than a physiological problem. Originally developed to bypass the blocked or missing Fallopian tubes of infertile women, IVF treatment has expanded to cases of male infertility due to poor sperm motility or low sperm count. In these cases, the woman may be physiologically normal reproductively, but nonetheless must undergo

hormonal stimulation, sonargrams, and laparoscopy. Health care professionals so take it for granted that the most sophisticated techniques will be sought for correction of patients' problems that they rarely question patients on their motivations to undergo discomforting, expensive, and possibly dangerous treatments. Despite our culture's emphasis on motherhood, men are often the dominant partner in reproductive decisions. The increasing popularity of the use of IVF treatment in cases of male infertility is understandable in the light of men's investment in biological parenting and women's willingness to take on the physiological responsibility for treatment. (p. 117)

This article reviews the literature about IVF treatment to support the ideas of increasing demand for infertility treatment; that increased public awareness about infertility treatments has led to an expansion of IVF clinics; that IVF technology is not new; and health professionals rarely question patients on their motivation to undergo sometimes discomforting treatments.

The medical perspective so imbues interactions between patients and health professionals that patients' "lifeworld" concerns and hesitations are frequently ignored or discounted. (p. 123)

The author states that:

Despite our culture's emphasis on motherhood, men are often the dominant partner in reproductive decisions ... In actuality, it is not that men *per se* control reproductive decisions, but that the dominant partner does, and in our society, the dominant partner is likely to be the man. (p. 124)

The author concludes:

I am not persuaded that the new reproductive technology makes women into victims, but I also do not think they are acting entirely autonomously. The dynamics of participation in such treatment illuminates issues of men's domination in reproduction and the extent to which women can truly control their bodies when faced with personal, psychological, familial, and community pressures to produce a biological child. (p. 126)

McShane, P.M. 1988. "In Vitro Fertilization, GIFT and Related Technologies — Hope in a Test Tube." In *Embryos, Ethics, and Women's Rights: Exploring the New Reproductive Technologies*, ed. E.H. Baruch, A.F. D'Adamo, Jr., and J. Seager. New York: Harrington Park Press.

Category

Editorial

Summary

This article discusses the various aspects of IVF, GIFT, and related technologies. It concludes:

In vitro fertilization (IVF) is demanding, expensive and inefficient. Nevertheless, tens of thousands of couples have undertaken the procedure because of their intense desire to have a biological child. Modifications of the current IVF process — simplification of ovulation induction and prediction of successful cycles; use of ultrasound instead of laparoscopy for egg retrieval; freezing of excess embryos for later replacement; and the substitution of GIFT (gamete intra-fallopian transfer) for IVF when it is indicated — may increase its acceptability to couples and improve success rates. Meanwhile, IVF has had tremendous impact on our understanding of fertility and should help physicians in their approach to infertility in the future. It has also ushered in a new era of genetic engineering whose potential we have not yet begun to realize. (p. 31)

Mahlstedt, P.P., and D.A. Greenfeld. 1989. "Assisted Reproductive Technology with Donor Gametes: The Need for Patient Preparation." *Fertility and Sterility* 52: 908-14.

Category

Prescriptive

Summary

This article examines issues concerning the use of donor gametes under the following headings: impact of infertility on the decision to use donor gametes; major issues concerning donor gametes (secrecy, donor anonymity, and "multiple parents"); social attitudes toward the use of donor gametes; and medical attitudes toward the use of donor gametes.

The authors conclude:

There are certainly no definitive answers to the questions raised by the use of donor gametes in reproduction, as there are no definitive answers

to any of life's most difficult questions. The loss of fertility is usually an unexpected, invisible, deeply painful wound for those couples who are considering the use of donor gametes. As they address the psychological issues of these techniques, they must also heal the wounds created by infertility. This type of grieving and examination of feelings takes time and information. (p. 913)

Murphy, J. 1984. "Egg Farming and Women's Future." In *Test-Tube Women: What Future for Motherhood?*, ed. R. Arditti, R.D. Klein, and S. Minden. London: Pandora Press.

Category

Editorial

Summary

According to the feminist author, the patriarchal practice of removing eggs from women's bodies (IVF) is more aptly described as "egg farming." This paper describes how women's eggs have become a sought-after commodity. It discusses the implications of egg farming for women's lives and women's future. (p. 68)

Reproductive technology challenges women's biological connection to our eggs by seizing control of the release, fertilization, and reimplantation of eggs in women's bodies. Women challenge reproductive technology by asserting our biological claim to eggs in order to prevent further exploitation of our bodies by patriarchal egg harvesting ... since the egg farming of women's bodies currently exists within patriarchy, and is carried out for patriarchal ends, we must establish control over our eggs. We must challenge egg farming by establishing our bodies as other than "reproductive bodies." (p. 74)

Needleman, S.K. 1987. "Infertility and In Vitro Fertilization: The Social Worker's Role." *Health and Social Work* 12 (2): 135-43.

Category

Prescriptive

Summary

The inability to have children may provoke a life crisis for a couple, and infertility itself is usually stressful. After examining the psychosocial impact of infertility and the various options available to infertile couples, this article describes a hospital-based IVF program and the social worker's role in supporting patients through complicated and anxiety-producing medical procedures.

Notman, M. 1984. "Psychological Aspects of AID." In *Infertility: Medical, Emotional and Social Considerations*, ed. M.D. Mazor and H.F. Simons. New York: Human Sciences Press.

Category

Editorial

Summary

This paper examines the psychological aspects of DI, concluding with an emphasis on the crucial role of support from a sensitive environment, and the availability of "helpful people" for couples and for children, if the procedure is to be successful.

Novaes, S. 1983. "La procréation par insémination artificielle: vers une analyse de la dynamique sociale." *Social Science Information/Information sur les sciences sociales* 22 (1): 139-48.

Category

Editorial

Summary

This paper examines the practice of IVF in France within a sociological perspective. It notes that the desire to have a child is governed in part by sociocultural beliefs. This sociological inquiry considers IVF not as a practice but as a therapy conforming to social norms that govern human biology and reproduction. The father's role changes from one who impregnates to one who undertakes partial responsibility for the child. The doctor's role also is redefined. If IVF were defined as a medical act, then the doctor legally would be responsible for the consequences.

IVF challenges the family's reproductive autonomy. Reproductive capacity becomes a transmissible property, which the family may cede to another. The doctor, the donor, the sperm bank, and the intermediary become new controls able to offer or retain the means to reproduce. Sperm banks offer a means of bypassing natural limits to reproduction. Childbearing is no longer the sole and legitimate property of the heterosexual couple. Donating sperm is not a parental act, but a social act of generosity toward sterile couples. Also, the existence of sperm banks permits society to regulate infertility as a medical act apart from the couple's sexual life.

Reading, A.E., and J. Kerin. 1989. "Psychologic Aspects of Providing Infertility Services." *Journal of Reproductive Medicine* 34: 861-71.

Category

Review

Summary

Psychologic issues enter into all aspects of providing infertility services. At the onset the infertile are faced with decisions regarding treatment options. Treatment involves uncertainty and lack of control and exposes the couple to the possibility of failure. The introduction of IVF and gamete intrafallopian transfer exposes a proportion of couples to successive experiences of failure. These treatments have implications for emotional processing; some factors can increase the likelihood of impaired coping. Specific ways of dealing with the psychologic needs of infertile couples at all stages of their treatment can be helpful. (p. 861)

This paper reviews the following: information exchange; decision making; stress from infertility and its treatment (psychological profiles of infertility patients and psychological stress of treatment); infertility and sexual and marital function; and psychological treatment (needs of couples and treatment goals, studies on psychological treatment, enhancing coping resources, cognitive behavioural approaches, and sexual and marital therapy).

The frustration of a goal as important as having children inevitably raises many psychologic issues. Parallel with medical management, attention needs to be given to psychosocial issues. As breakthroughs in treatment continue, couples and individuals are faced with many more options. For the successful, new advances bring rejoicing, but for those who fail, their struggle is protracted further. At a minimum, participants in the "fertility chase" deserve clear information as to their chances of success as well as to the potential drawbacks — emotional, financial and medical — of trying. Imparting accurate, balanced information is only part of the process of achieving an informed decision. Consideration also needs to be given to the distorting forces that can operate over such emotive topics. Staff members dealing with the infertile need to be able to uncover psychologic concerns, conflicts between partners and unmanaged stress or anxiety. It is not enough to focus exclusively on the reproductive organs. Nowhere is the term *holistic* more applicable than to this population. Early identification of psychologic issues affords the opportunity to address those issues before they exact a toll. (p. 870)

Rosenfeld, D., and E. Mitchell. 1979. "Treating the Emotional Aspects of Infertility: Counseling Services in an Infertility Clinic." *American Journal of Obstetrics and Gynecology* 135: 177-80.

Category

Prescriptive

Summary

This paper describes a counselling service for infertile couples. The authors conclude that there was a "direct correlation between those that participated fully in the exercises and those that had the most movement during the counseling sessions." (p. 177)

Rothman, B.K. 1984. "The Meanings of Choice in Reproductive Technology." In *Test-Tube Women: What Future for Motherhood?*, ed. R. Arditti, R.D. Klein, and S. Minden. London: Pandora Press.

Category

Editorial

Summary

The new reproductive technologies are heralded for their choice-giving capacity. This article considers the negative side — the choices lost as the technologies develop. The author concludes:

... that individual choice, while it must always be defended, must be understood in the context of the society which structures the choices available to individuals. The individual right to choice is an absolute necessity, but not alone sufficient to ensure an ethics of reproduction. (p. 23);

... and choice, we claim, rests firmly on information ... Technology is also about information, and about choice; (p. 23)

... information may expand the opportunity for choices, but it certainly does not guarantee whose choices will be honored; (p. 25)

... we thought that information would give us power. What we perhaps overlooked is that it is *power* which gives one control over both information and choice; (p. 26)

... we must not get caught into discussions of which reproductive technologies are "politically correct," which empower and which enslave women. They ALL empower and they ALL enslave, they all can be used by, for, or against us. We will have to lift our eyes from the choices of the individual woman, and focus on the control of the social system

which structures her choices, which rewards some choices and punishes others, which distributes the rewards and punishments for reproductive choices along class and race lines; (p. 32-33)

... there will never be "free" choice, unstructured reproductive choice. But the structure in which choices are made should, and I believe ultimately can, be made fair, ethical, moral. Individual rights to information and to choice are an absolute necessity for such a system, but are not alone sufficient to ensure an ethics of reproduction; (p. 33) and

... the next step in the politics of reproductive control is the politics of social control; (p. 33)

Ruddick, W. 1988. "A Short Answer to 'Who Decides?'" In *Embryos, Ethics, and Women's Rights: Exploring the New Reproductive Technologies*, ed. E.H. Baruch, A.F. D'Adamo, Jr., and J. Seager. New York: Harrington Park Press.

Category

Editorial

Summary

Whatever the moral and metaphysical complexities of reproductive decisions, the answer to "Who should decide?" is clear. Women, and only women, should make decisions about their own childbearing. This does *not* exclude the concerns of men they care for, or the advice of men they trust. But it does exclude men, publicly or privately from having a veto or decisive voice in questions about the number, timing, or aborting of pregnancies, or the method of conception — or, the question of adoption versus conception.

... these new techniques make assertion of a woman's rights of decision all the more important. Thanks to Ruth Hubbard (1984), Barbara Katz Rothman (1986) and others, we are becoming aware of technocratic pressures on conception, pregnancy, and childbirth. These pressures merely increase the control which experts and professions already exercise over women's reproduction. (p. 73)

Ruddick discusses two common sources of professional pressure: First, "... (modern) physicians speak of their professional commitment to Respecting and Prolonging Life ... these abstract goals make medically assisted conception and fetal therapy ... commendable." Second, when professional abstractions are powered by professional optimism, pressure on patients is even greater. "Optimists typically disregard probabilities of success, low or high; they are moved rather by *possibilities*, confident in their capacities to beat the odds." (p. 74)

Schinfeld, J.S., T.E. Elkins, and C.M. Strong. 1986. "Ethical Considerations in the Management of Infertility." *Journal of Reproductive Medicine* 31: 1038-42.

Category

Editorial

Summary

These authors are from the Department of Obstetrics and Gynecology and Program on Human Values and Ethics, University of Tennessee College of Medicine, Memphis.

Ethical issues arising in the day-to-day practice of infertility treatment are important and sometimes difficult. A couple's infertility problem usually has affective and social dimensions, sometimes disrupting their lives. Responsible care involves dealing with these psychosocial factors, including counselling and striving for informed patient decision making. The ethical problem of whether to provide treatment when the probability of success is low is sometimes complicated by a couple's desperate desire for fertility. In such cases the physician weighs various factors, including the risks of the procedure, the harm that might result from continuing infertility and the degree of the couple's understanding of the pros and cons ... Also, questions about when to refer or terminate the workup and therapy involve ethical reflection about potential conflicts of interest. (p. 1038)

At a time when bioethical discussions in reproductive medicine center almost solely on new technologies, it is important to reemphasize the basic issues concerning the relationship between the physician and the infertile couple. Doctors must not only master the subspecialty surgical and medical skills involved but also be familiar with the commonly associated social, sexual and ethical problems. Some ethical issues arise in day-to-day practice in the treatment of infertility. Some of them arise in other areas of obstetrics and gynecology, but they become especially sensitive when a couple has lost control of their lives by failing to conceive. A physician has specific responsibilities under these circumstances. (p. 1038)

This paper also discusses the following issues: informed consent, whether to proceed with treatment, truth telling, and professional obligations such as pride versus consultation.

Schuker, E. 1988. "Psychological Effects of the New Reproductive Technologies." In *Embryos, Ethics, and Women's Rights: Exploring the New Reproductive Technologies*, ed. E.H. Baruch, A.F. D'Adamo, Jr., and J. Seager. New York: Harrington Park Press.

Category

Editorial

Summary

Citing researchers, this author discusses four principles regarding the psychological effects of the new reproductive technologies: (1) specific circumstance of birth or parenting will inevitably be given psychological meaning; (2) human parenting does not require a biological connection; non-biological parents can be equally effective nurturers; (3) good parenting involves a psychological interaction beginning at birth, so that early and permanent opportunity for attachment is important for normal development; and (4) new technologies relieve the psychological pain of infertility and provide benefit by giving some individuals the opportunity to be parents.

Having discussed these four basic psychological principles, I want to mention some other issues raised by the new technologies of reproduction. My personal bias is toward minimizing social controls and maximizing voluntary choice in the application of these technologies. This is because I fear that advocates of social controls over others' decisions about their bodies and lives tend to be expressing their own prejudices and deep psychological needs and their own wishes to dominate and control others for their own purposes ... Whether the woman is older or younger, I feel that each individual must make the choice ... in an environment that provides educational information, psychological support, and the best available medical skills. (p. 145-46)

Seibel, M.M., and S. Levin. 1987. "A New Era in Reproductive Technologies: The Emotional Stages of In Vitro Fertilization." *Journal of In Vitro Fertilization and Embryo Transfer* 4: 135-40.

Category

Prescriptive

Summary

These authors observed a repetitive behavioural pattern associated with the seven steps of IVF. They highlight the enormous psychological stress associated with each of these steps in hopes that individuals working

with these patients, and in particular the psychiatric community, will be better able to understand and treat couples participating in IVF.

They make the following suggestions: adequate time must be allowed for the initial interview; an understanding counsellor must be available to couples for frequent communication; and emotional counselling should be a required, enforced component of the IVF program.

Finally we must be continuously sensitive to both the enormous vulnerability of these patients and the enormous impact we have at each step of this new era in reproductive technology. (p. 139)

Shannon, T. 1988. "In Vitro Fertilization: Ethical Issues." In *Embryos, Ethics, and Women's Rights: Exploring the New Reproductive Technologies*, ed. E.H. Baruch, A.F. D'Adamo, Jr., and J. Seager. New York: Harrington Park Press.

Category

Editorial

Summary

The writer raises the following issues and questions:

If the purpose of medicine is to restore a person to health, in what respect is someone who is infertile unhealthy? ... Is infertility a disease? ... how do we categorize infertility so that we can understand its place in the discipline of medicine? ... How does IVF affect infertility? ... If the individuals were infertile before IVF, they are just as infertile afterwards ... The couple needs to understand that IVF does not resolve infertility ... these interventions are ... compensations, rather than cures. [One wonders then if the] feelings of infertility or inadequacy may remain after successful IVF therapy. (p. 155-57)

The writer states that there is no U.S. national registry to which research and practice data are reported. He believes that agreement needs to be reached on how to determine and report success rates.

Does one report, for example, the numbers of pregnancies obtained, the pregnancies per laparoscopy, the pregnancies per embryo transfer, the live births per pregnancy, the live births per laparoscopy, or the live births per transfer? Obviously the method of reporting makes a huge difference in what the success rate appears to be. Consistency is called for here. (p. 159-60)

He concludes:

IVF is in place, it is accepted as part of the clinical treatment of infertility, and it is understood as another blessing of science and medicine. Yet few of the individuals who developed this technique questioned its impact on society or on women, its impact on already

scarce medical resources, or its relation to other technologies such as genetic engineering. We have developed a technology that has profound consequences for the individual and, in typical American fashion, we assume that all will be right — or that any problems can be solved later. (p. 164)

Simons, H.F. 1984. "Infertility: Implications for Policy Formulation." In *Infertility: Medical, Emotional and Social Considerations*, ed. M.D. Mazor and H.F. Simons. New York: Human Sciences Press.

Category

Editorial

Summary

This paper explores some issues involved in the formulation of policies affecting infertility. Under the heading, "Controversial Aspects of Infertility Treatment," the author discusses infertility treatment for the poor. She asks the question with regards to public funding of infertility treatment: "Must low-income couples remain childless because they lack the means to pay for proper care?" Another equity issue raised is the treatment of single women either for fertility problems or for infertility. "One must question the existence of a double standard whereby those paying out-of-pocket may obtain whatever procedures they can afford." (p. 67)

Spencer, L. 1987. "Male Infertility: 5. Psychological Correlates." *Postgraduate Medicine* 81: 223-28.

Category

Prescriptive

Summary

The author notes that since infertile couples grieve over their loss of potential life, the feelings are much the same as those experienced by persons grieving over death. A physician sensitive to the psychological stress these patients undergo during diagnosis and treatment can do much to prepare them for "what they may feel, moderate their reactions, and help them move on to acceptance." (p. 223) The paper discussed typical patient responses and listed 12 specific supportive actions that managing physicians can take.

Stotland, N.L. 1985. "Contemporary Issues in Obstetrics and Gynecology for the Consultation-Liaison Psychiatrist." *Hospital and Community Psychiatry* 36: 1102-1108.

Category

Editorial

Summary

This paper describes the context of some contemporary reproductive issues for which psychiatric consultation is sought, and it presents specific cases and concerns in the area of physical illness, genetics, fertility and infertility, obstetrics, and gynaecology.

Couples seeking IVF must undergo intrusive physical and hormonal assessments of both partners, intricate hormonal induction of ovulation, repeated laparoscopic ovum retrieval, ultrasonography, countless trips to laboratories, and anxious, exquisitely timed attempts at implantation. All of these procedures interpose machinery and technology into the delicate processes of human reproduction: coitus becomes mechanical ... This intrusion has complex psychological effects. Patients are grateful that science offers hope of relief for reproductive problems. However, the possibility of successful intervention may delay a couple's resignation to, in many instances, unchangeable biological realities. (p. 1103)

The writer asks some pertinent questions:

What constitutes "informed consent," especially for a newly devised procedure whose long-term consequences will not be known for many years, or for a procedure performed on a young patient whose development may have a major impact on her feelings about it in later years? Where do consumers' rights end and doctors' rights to govern their behavior begin? Who shall be the gatekeeper for procedures too technical or expensive to be available to all, and for those resulting in the end or beginning of human life? (p. 1103)

Sundby, J. 1988. "Psychological Consequences of Unwanted Infertility, Its Investigation and Treatment: A Literature Survey and Pilot Study." *Nordisk Psykiatrisk Tidsskrift* 42: 29-33.

Category

Review

Summary

This article investigates the need for guidance in infertility investigation. The writer concludes that counselling should supplement infertility services in response to "the enormous need for emotional support in this group." (p. 32)

Taymor, M.L. 1990. "Emotional Factors." In *Infertility: A Clinician's Guide to Diagnosis and Treatment*. New York: Plenum Medical Book.

Category

Review

Summary

Is there a need for routine psychiatric evaluation in the management of the infertile couple? Is the ideal infertility specialist a gynecologist who has also been psychiatrically trained? Unfortunately, few gynecologists have the time, or inclination, for such intensive emotional exploration with each patient; but the infertility specialist or gynecologist should at least be sufficiently aware of the importance of emotional factors and recognize the patient who needs psychiatric help. Surely, these are the minimal qualifications for all those who attempt to treat the infertile couple.

... Therefore, I feel it is often more practical for the fertility specialist to serve as the screening physician, to practice preventive psychiatry by singling out the patient with significant emotional conflicts for whom psychiatric consultation can be arranged, and, finally, to urge psychiatric consultation for all patients with unexplained infertility. (p. 40-41)

Uniacke, S. 1987. "In Vitro Fertilization and the Right to Reproduce." *Bioethics* 1: 241-54.

Category

Editorial

Summary

An important general question of reproductive ethics, seldom isolated and discussed outside the issue of population control, is whether people have a right to reproduce.

... In this paper my own interest in the right to have children, which I interpret here as the right to reproduce, centres on the way in which this right might be brought to bear in determining whether finite resources

should be directed towards in vitro fertilization (IVF), rather than deployed in other areas of health care, or in other fields. (p. 241)

The question of how serious an affliction involuntary infertility is must be faced, whether we decide to consider IVF as a form of compensation, or to rest the justifiability of funding the procedure solely on grounds of compassion. Certainly involuntary loss of reproductive capacity is significant. More often than not hopes are dashed, and always one important area of choice and development is closed off. But the severe, sometimes unrelievable anxiety and feelings of worthlessness derive from the view that having children is not simply a worthy avenue of personal development, but an essential good like life, health, and basic education. Recognition of this should not lead us to downgrade this severe anxiety in decisions about future priorities and the relative merits of alternative courses of action, if this underlying view is indeed an important one to maintain and defend. But many, including myself, believe it is not. And those who emphasise procreation as essentially optional and decry the significant influence of social interest and expectation in personal decisions on this matter, ought not to assume, as they often do, that the having of children is a substantial claim right. (p. 254)

Van Hall, E.V. 1985. "The Gynaecologist and Artificial Reproduction." *Journal of Psychosomatic Obstetrics and Gynaecology* 4: 317-20.

Category

Prescriptive

Summary

The gynaecologist and the infertile couple have the same object in view: to find the cause of the infertility and institute a treatment that will lead to pregnancy and eventually to the birth of a healthy child. Unlike other forms of medical care, which are usually directed at the cure of a disease; the management of infertility is aimed primarily at the attainment of a social achievement. It is therefore hardly surprising that during the usually long period of infertility management, emotional and psychosocial factors play an important part in the doctor-patient relationship. This certainly is especially the case when artificial reproduction techniques like insemination with donor sperm (AID) and IVF (IVF) are used ...

In our department the infertility investigation is built up in a systematic way, allowing time to elapse between different steps unless gross abnormalities are found. Under these conditions, we have found that spontaneous pregnancy occurs in approximately 40% of the women within 6 months after HSG and approximately 30% within a year following laparoscopy when these procedures reveal minor or no abnormalities. In my opinion, it is extremely important to exercise the patience to allow such spontaneous pregnancies to occur without

medical interference for two reasons: (1) medical interference is not necessary and might even be harmful; and (2) a spontaneous pregnancy will be the couple's *own* pregnancy and not the doctor's which enhances their feeling of self-esteem and independence. (p. 317)

I would like to stress once again here that when no cause for the infertility is found after a complete and thorough investigation one should refrain from further diagnostic procedures and questionable treatments except as part of a well-controlled scientific study. On the contrary, one should explore the possibility that, especially in long-standing cases of unexplained infertility, there might be no wish at all to have a child ...

When pregnancy is not achieved despite a long and thorough investigation and intensive treatment, a frustrating situation for both gynaecologist and patient is again created. Often under the pressure from the couple, this situation leads to an endless reiteration of diagnostic tests and often unnecessary additional treatment. Women are operated on over and over again, and couples travel from one doctor to the other unnecessarily prolonging their own torment.

... This decision should be taken with sufficient determination to withstand the couple's natural urge to continue. The gynaecologist should overcome his own frustration, admit his inability, and direct his attention and energy to helping the couple to cope with their grief. Sometimes it is less painful to endure a negative certitude than a positive incertitude. (p. 318)

In the case of IVF, I am of the opinion that this form of treatment should be reserved for those couples in whom the infertility is caused by an organic impediment of physiological fertilization. IVF should not be offered as an easy short-cut in couples with unexplained infertility or infertility factors that can be treated otherwise ...

I am convinced that the psychological stress during these cycles must be tremendous, and there is no doubt in my mind that psychological stress can affect the delicate mechanism of implantation and the course of early pregnancy.

Although I am not yet able to prove the validity of this statement, I dare to predict that more attention to the psychological aspects of embryo transfer and an adequate and professional psychological preparation of these women will virtually improve the pregnancy rates after IVF. (p. 320)

- Waltzer, H. 1982. "Psychological and Legal Aspects of Artificial Insemination (A.I.D.): An Overview." *American Journal of Psychotherapy* 36: 91-102.
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Category
Analysis

Summary

This paper focusses on the reproductive method of AI by third-party donor. After presenting studies on the psychology of AI, the author concludes:

Artificial insemination is a reproductive procedure that is coming into greater use. The number of children born via this method is unknown but estimated in the range of 500,000. Both conscious and unconscious psychodynamic factors are present that may be beneficial or detrimental to the outcome. There is general agreement that the choice of A.I.D. is not necessarily reflective of neurotic needs. The birth of the A.I.D. child might bring forth neurotic responses ranging from mild to severe. There seems to be no justification to recommend psychological or psychiatric examination routinely for couples requesting artificial insemination. (p. 101)

- Warren, M.A. 1988. "IVF and Women's Interests: An Analysis of Feminist Concerns." *Bioethics* 2: 37-57.
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Category
Editorial

Summary

Thus far, little of the public and professional debate about the ethics of *in vitro* fertilisation (IVF) and other new reproductive technologies (NRTs) has focused upon the possible negative effects of these technologies on women. There is endless discussion of the moral status of the fertilized ovum or pre-embryo, and its possible moral rights. Theologians and non-religious critics debate the propriety of conceiving human beings "artificially," that is, without heterosexual intercourse. Concern is also voiced — and appropriately so — about the possible physical or mental effects of technologically assisted reproduction upon resulting children. But with the exception of a small group of feminist critics, few have paid much attention to the dangers to the women who serve as experimental subjects in reproductive research and, indirectly, to all women. (p. 37)

The paper recommends:

... it is essential that every government body with responsibility for the regulation of the NRTs, every ethical oversight committee, and every public agency which funds reproductive research be at least 50% composed of women. (p. 44.)

More to be feared, perhaps, is the covertly coercive force of social expectation. New technologies often have a momentum of their own; once they exist, they are likely to be seen as pragmatically and morally superior to any less highly technological option, even when the reverse may be the case. Some feminists argue that the very existence of IVF as a treatment for female infertility increases the pressures on infertile women to keep on trying until they have exhausted every possible treatment for their infertility. The prevailing pronatalist ideology may thereby be strengthened, and the social stigma and suffering of all infertile women increased. (p. 45)

Feminists are rightly concerned that if the NRTs continue to be developed and delivered by largely male teams, women's interests will not be as well served as they ought to be. (p. 53)

There is a need for more participation by women in all aspects of the practice, funding, and supervision of such biomedical research, as well as in the provision of medical care. (p. 53)

Even with greater participation by women in the development of the NRTs, there will remain some danger that the NRTs will contribute to the subtle erosion of women's reproductive autonomy. (p. 54)

One element of a more adequate societal response to that problem [involuntary infertility] is the better dissemination of knowledge about the preventable causes of infertility ... (p. 54)

Wright, J., et al. 1989. "Psychosocial Distress and Infertility: A Review of Controlled Research." *International Journal of Fertility* 34: 126-42.

Category

Review

Summary

Three hypotheses have been most often cited on the link between infertility and psychosocial distress: (1) psychosocial problems trigger infertility; (2) infertility triggers psychosocial distress; and (3) there is an interactive causal relationship between infertility and psychosocial distress. The controlled research on these hypotheses was reviewed. The thirty publications that met inclusion criteria provide convincing evidence that, taken as a whole, patients diagnosed and treated in infertility clinics show significantly higher levels of psychosocial distress than do control groups. As well, in general, female patients score higher

on psychosocial distress measures than males. However, the authors conclude that research designs to date have failed to control crucial variables that permit conclusive empirical tests of the three hypotheses. The paper closes with recommendations for future research that would accelerate the evaluation of scientific data available on the subject. (p. 126)

There is little reason to expect that modern society will witness a decrease in infertility or the demand for advances in medical solutions. Clinicians and researchers are evidently preoccupied with the psychosocial dimension of infertility. Although research on the medical diagnosis and treatment of infertility has progressed recently, advances on the psychosocial dimensions of infertility have, in our opinion, lagged behind. This can undoubtedly be partly explained by the enormous ethical, measurement, and practical problems associated with research on psychosocial dimensions of infertility. However, researchers would probably contribute at a higher rate if experimental hypotheses were elucidated in operational and refutable terms; and design features were chosen that are more sensitive to problems of (a) diagnostic precision, (b) homogeneity of patient population, (c) adequate sample size, (d) time (evolution) variables, and (e) statistical analyses required for evaluation of the simultaneous impact of multiple independent and dependent variables. (p. 140)

3. Summary of Research Studies and Writings

The Rank 1 studies may be divided into four major groups: (1) studies concerned with the impact of infertility treatments on women, couples, men, families, and children. These studies examined such psychosocial conditions as stress, anxiety, sexual dysfunction, self-esteem, and self-worth; (2) studies that examined the practitioner-patient relationship; (3) studies that emphasized or examined the role of support systems (e.g., counselling for individuals and groups, assisting decision making, etc.); and (4) studies that investigated a particular treatment, such as IVF, DI, or laparoscopy.

Some studies dealt with other issues. These will be treated separately under the heading "Other Issues."

Rank 2 studies may be divided based on the following: (1) impact; (2) practitioner-patient relationship; (3) support; (4) ethics; and (5) feminist perspectives.

Rank 1 Studies

Case studies and/or surveys or questionnaires dealing with the psychosocial implications of infertility treatments were designated Rank 1.

Impact of Infertility Treatments

Much research was concerned with the effects of infertility treatments on participants. The 1985 study by Haseltine et al. tried to determine what aspects of the IVF program caused major problems for couples. The study concluded that, because of their tendency to repress anxiety arising from fear of being dropped from the program, women may be at greater risk of psychosomatic illnesses. Williams (1989) interviewed 20 Canadian couples in an IVF program to examine the women's in-treatment experiences. A dominant theme was that women had a profound fear of being "cancelled" if they did not pass the required tests or respond to hormonal treatment. The researcher noted that women experienced stress related to various treatment stages and waiting for the pregnancy test was the most stressful.

Regarding sexual dysfunction, Fagan et al. (1986) found that 19 individuals among 45 couples studied experienced sexual dysfunction or psychological disorders. Sexual dysfunction was more likely to be found among couples with unexplained infertility. The incidence of dysfunction or psychological disorder, however, was not higher than that among the general population. Freeman et al. (1985) conducted a psychological evaluation of patients participating in a university-based IVF-ET program. These researchers found that 50 percent of women and 15 percent of men reported that infertility was the most upsetting experience of their lives. Two-thirds of women also reported that infertility treatment had changed their sexual relationships, and sex had become less pleasurable. Twenty-nine percent of individual scores suggested dysfunctional emotional distress or personal difficulties; half the sample demonstrated effective functioning and ability to withstand stress.

Drake and Grunert (1979) studied the incidence and pattern of sexual dysfunction at the time of post-coital testing in affected individuals. They found that a major psychological abnormality, which can contribute to infertility, is male sexual dysfunction; in some couples, there was a pattern of mid-cycle sexual dysfunction. They concluded that factors contributing to this include the "this-is-the-night" syndrome, a change in the purpose of sexual intercourse, the stress of third-party clinical testing, and self-doubt about adequate future performance. Bell's (1981) interview data suggested that couples with previously satisfactory sexual relationships may develop secondary dysfunctions arising from infertility-related anxieties.

The studies of Harrison et al. (1981 and 1986), which reviewed the role of stress in couples who had experienced infertility for at least three years, found that infertile couples had higher mean anxiety scores on all emotional factors than the control group. O'Moore et al. (1983) showed female patients were more prone to anxiety and guilt feelings than female controls or male patients, based on comparative data. These researchers also reported that the husbands of infertile women showed considerable defensiveness.

Berg and Wilson (1991) found significant fluctuations in psychological functioning over three years in couples in medical infertility treatment. They documented acute stress reactions related to diagnosis and initial phases of treatment, which diminished over time. This stress was overlaid by a chronic strain response that intensified as treatment continued. Levels of psychological functioning varied from the first year to the third year of treatment, with the latter being the most difficult. Psychological strain in these couples was comparatively higher, and indices of marital and sexual satisfaction were at their lowest levels. The significance of emotional stress seemed to be particularly elevated early in the infertility treatment for couples in Frank's study (1990a) and for people who had been in treatment for longer than average periods.

Harris (1989) proved the theory that patients undergoing treatment experience more emotional problems and less marital satisfaction than women who have terminated treatment.

Link and Darling (1986) investigated life satisfaction in couples undergoing treatment. They found clinical levels of depression among women undergoing infertility treatment and higher levels of dissatisfaction among women whose husbands did not respond to the survey.

Downey et al. (1989) investigated depression among women undergoing treatment. They found that, whereas these patients were not different from the controls when self-reporting on partner satisfaction, sexual function, or self-esteem, they did perceive themselves to have been affected by their inability to conceive: 49 percent reported changes in their sexual functioning and 74.6 percent reported mood changes.

Lalos et al.'s (1986) longitudinal study found that most symptoms experienced by infertile women and their partners could be classified in terms of depression, guilt, and isolation. Women tended to manifest more depressive and guilt symptoms than men, who often suppressed or even denied emotional reactions. These researchers concluded that the nature of treatments often caused sudden feeling fluctuations as well as unrealistic expectations and depression, and may increase the risk of neurotic disturbances.

Lalos et al. (1985c) investigated the psychological effects of medical investigation and infertility treatment. The study concluded that negative effects on sexual life were recorded in all individuals and were associated with the planning of intercourse.

McGrade and Tolor (1981) considered the impact of infertility on self-worth, self-image, sexuality, and perceived influences on the couple's sexual function. Both sexes recognized the emotional distress, tension, and strain. Women suffered a greater incidence of injury to self-esteem than men. Women were more likely than men to question their sexuality, even though both sexes reported a high incidence of sexual dysfunction. Patients' sex life tended to deteriorate as fertility evaluation progressed.

Burns (1990) examined the long-term effects of infertility on the psychosocial functioning of families. This study found that most subjects

(85 percent) rated infertility as a negative experience causing varying degrees of disruption and alteration in their lives. Again, men tended to find this disruption less severe than women. Seventy-six percent reported conflict in their marriages — a significantly higher percentage than in the control group. Subjects with a history of infertility reported far more problems in themselves, their marriage, their parenting, and their children.

Soper (1990) examined the impact of infertility on women's self-image, level of ego maturity, careers, and relationships with family and friends. This researcher found that subjects overwhelmingly reported that they felt as though their lives were on hold and that infertility had negatively influenced their self-images and career plans. Hirsch and Hirsch (1989) considered the impact of infertility on marriage and self-concept. Their findings were similar to those of other studies in that infertile individuals experienced greater dissatisfaction with themselves and their marriages, and that women experienced greater discontent over time and had greater emotional investment than men. As treatment continued, men seemed to adapt better to the intervention, while women found it took an increasing toll on their lives. Likewise, Chan et al. (1989) in Hong Kong showed that women had significantly higher scores on anxiety measures than their spouses.

Demyttenaere et al. (1988) found a significant relationship between initial trait anxiety levels and the number of treatment cycles necessary for conception. They also found that women who had early spontaneous abortions initially were more stressed than others who became pregnant. There was no significant correlation between duration of infertility and trait anxiety. This argued against the current view that women suffer from psychological problems as a result of the duration of infertility investigations and treatment. They stated, however, that a relationship exists between lengthy infertility and neurotic anxiety.

Practitioner-Patient Relationship

A few researchers examined the relationship between physician and patient in infertility treatment. In an investigation of why some patients discontinue treatment, Hofmann et al. (1985) found that one reason for ending treatment was a problematic physician-patient relationship.

Ouellette (1988) wrote that the media, the public, and the medical establishment generally portray infertility as a disability that the doctor has the will, desire, and duty to relieve. Sexuality is falling into the hands of doctors. A new marketplace is being built to retail human reproduction.

Burns (1990) suggested that physicians and other professionals must take greater responsibility in helping couples define the realistic parameters of their medical treatment.

James and Hughes (1982) investigated the psychological well-being of women suffering from anovulation after attempted treatment by clomiphene citrate. They found that the resolution of the "problem" is influenced as much by the individual's adaptive capacity as by treatment outcome. In

considering the degree to which investigation and treatment should be pursued, they believe two factors are important in arriving at a successful psychological outcome: awareness on the part of the attending physician and sensitivity on the part of male and female partners to long-held fantasies and role expectations.

Support Systems

Throughout the literature, researchers concluded that individuals and couples need support as they deal with the stages of infertility treatment. Some studies saw a place for highly qualified support staff who understand the procedures and the range of emotions that participants may be experiencing. Holmes and Tymstra (1987) and Leiblum et al. (1987b) recommended psychological support from IVF personnel trained to know when to refer patients to other mental health professionals. Leiblum et al. (1987a) also stressed that adequate attention should be directed to the psychological and the physical aspects of IVF treatment. Goodman and Rothman (1984) reported on group sessions designed to help female patients manage infertility crises. They found that process-oriented, low leader-directed formats were beneficial.

Holmes and Tymstra (1987) noted that couples beginning treatment should receive written information emphasizing the low chances of success.

Lukse (1985) confirmed that infertility counselling reduced self-reported grief symptoms experienced by some infertile couples. Women improved in all areas of grief categories, while men remained essentially the same. The same was true for patients' self-concepts. These couples reported no significant changes in their feelings about their marital and sexual relationships after counselling.

Takefman et al.'s (1990) exploratory study revealed that the group that received only descriptive information on the investigative procedure reacted more positively to the investigation than the groups that received additional information about possible emotional and sexual reactions to the investigation.

Bresnick and Taymor (1979) and Bresnick (1981) found that long-term counselling had more impact than short-term counselling to decrease the emotional symptoms of guilt, anger, frustration, and isolation in women and for men. They wrote that infertility counselling, combined with medical diagnosis and treatment, can enhance the quality of life for many patients who have become victims of the "infertility crisis."

Women undergoing DI indicated that counselling would be beneficial (Reading et al. 1982). Psychological preparation could relieve doubts and anxieties over availability of staff and engender realistic expectations as to the likelihood of becoming pregnant each cycle. Wallace (1985) found that some patients misunderstood surgical information and most patients welcomed additional psychological preparation.

Since acceptance of childlessness is sometimes hampered by the persistent hope of a miracle, Lalos et al. (1985b) recommended professional support for participants in treatment.

Valentine (1986) was concerned with the implications for social work practice in fertility clinics and other health and mental health facilities serving infertile persons. The study indicated that medical practices should respond to the emotional needs of infertile people. This researcher believes that trained, skilled social work practitioners can meet these needs.

Stewart and Glazer (1986) stated that the IVF nurse can and should be instrumental in preparing patients for their IVF cycle, in supporting and comforting them throughout the cycle and afterward, and in promoting spouses' physical and emotional involvement.

Lalos et al. (1986) and Bresnick (1981) maintained that to cope with the crisis of infertility, couples require supportive counselling, separately and together, during investigation and medical treatment.

Frank (1990b) looked at gender differences in decision making about infertility treatment. The study emphasized the importance of including both partners in counselling concerning infertility decisions. Nurses should encourage couples to examine forces influencing their decision each time a new alternative is posed — especially by focussing on how stress influences the decision.

Callan and Hennessey (1988) found that women tended to be overly optimistic in their initial IVF attempts. Optimism generally declined with each attempt, and participants experienced considerable stress over several stages. They found that patients possibly needed the highest level of emotional support when they are not directly involved in the procedure; that is, while they wait at home. They found that counselling and support are critical if the attempt fails.

Lalos et al. (1985c) found that most couples overestimated their chances of having a child, and half of them expected a pregnancy within a few months. After two years, the need for professional support and counselling had increased. They recommend that, during periods of somatic investigation and treatment, repeated discussions about marital and sexual life should be initiated and psychosocial counselling offered.

In their finding that attention to treatment failure and success is important, Harrison et al. (1986) suggested that optimum benefit to patients might rely not only on providing good clinical ambience and pharmacological preparations, but also relaxation therapies such as autogenic training. Such training significantly lowered psychological and biochemical stress marker scores.

Fagan et al. (1986) recommended including psychological assessment of couples as a standard consultation procedure within the IVF protocol.

Link and Darling (1986) and Harper et al. (1985) demonstrated that women who undergo infertility treatment experience stress in various life areas. They recommended that clinicians encourage the couple's acceptance of themselves as they are, create a supportive environment

during treatment sessions, and direct them to other sources of assistance and support.

Specific Treatments

Surgery

Lalos et al. (1985b) examined the psychosocial impact of infertility two years after completed surgical treatment on 24 women (30 women initially). The researchers found that partners' feelings toward each other had deteriorated — especially among the men. The couples' sexual life had also deteriorated, especially among the women, and the emotional effect of the continued infertility was most pronounced among the women. Feelings of guilt among the men had intensified two years after the spouse's unsuccessful surgical treatment. Most participants had not tried to solve their fertility crisis two years after surgery. These researchers raised the idea that acceptance of childlessness is sometimes hampered by the persistent hope of a miracle. Wallace (1985) investigated the costs and benefits of this procedure and looked at whether the reason for having the operation accounted for differences in individual adjustment to and recovery from the operation. The study found that patients undergoing sterilization and infertility investigation were concerned about costs and benefits influencing fertility, menstruation, and sexual activity. Patients often misunderstood surgical information and welcomed additional psychological preparation.

Donor Insemination

Demyttenaere et al. (1988) investigated the relationship between state anxiety and the probability of conception in women entering a DI program. They found a statistically significant relationship between initial trait anxiety levels and the number of treatment cycles necessary for conception rather than the duration of infertility and trait anxiety. They claimed that their clinical experiences point to a relationship between lengthy infertility and neurotic anxiety.

Czyba and Chevret (1979) found that case histories of 62 couples whose insemination resulted in pregnancy were similar, involving the following: awareness of wanting a child while the woman does not conceive; investigation of sterility; discovery of the husband's sterility; adaptation; disappearance of guilt feelings; acceptance of DI; request for DI; conflict with medical profession; disturbing DI sessions, usually in the husband's presence; uneasiness at the onset of pregnancy; euphoric continuation of pregnancy; uncomplicated delivery; request for a second child by DI.

Macourt and Jones (1977) reviewed cases of 53 couples requesting insemination instead of adoption. There were 43 proven pregnancies resulting in 29 live births. They found no instances of hostility toward the child or other spouse. The pregnancies and deliveries were no more emotional than natural pregnancies and deliveries. They concluded that the excellent results may have been due to the considerable thought put

into the matter by couples before they were seen by the researchers and that DI had been the preferred choice.

Berger (1980) examined couples' conflicts and behaviour patterns after the identification of male infertility. Berger found a common conflict pattern: impotence, depressive mood and/or depressive equivalents in the husband, and hostility and guilt in the wife. The decision to pursue DI involves two problem-solving stages: coming to terms with the infertility and confronting the problems of DI. This researcher believed that secrecy involved in DI inhibits the working through of conflicts about infertility and DI. Berger recommended that serious discussion relating to DI might best be postponed for three to four months after completion of infertility work-up.

Berger et al. (1986) again looked at psychological patterns in DI couples. Part of the study involved a secrecy questionnaire. A brief survey of literature dealing with the psychological impact of DI was included. The researchers found that the discovery of infertility generates transient impotence, loss of self-esteem, and withdrawal among husbands and anger, guilt, and a wish to make reparations among wives. The DI procedure itself evokes oedipal conflicts. Couples should come to terms with the conflicts generated by the discovery of infertility before tackling DI. They found that among 58 percent of couples, at least one partner considered it psychologically useful to discuss their infertility with others. They concluded that even though secrecy may be useful, it may also interfere with the couple's acknowledgment and discussion of their problems through indirect sanction of denial and negation.

Harrison et al. (1981) examined the relationship between stress and AI. Two groups of patients were followed. One practised AI at home, while the other group was treated in hospital. Though the sample was small, the researchers suggested that the environment in which therapy takes place, rather than the treatment itself, may result in extra stress and possible anovulation.

Reading et al. (1982) evaluated psychological factors associated with attending a DI clinic. They looked at state anxiety levels before each insemination to identify stress levels involved and to monitor patterns of anxiety change during successive treatment cycles. They related these levels and patterns to whether pregnancy had or had not occurred. They also looked at attitudes toward insemination and childlessness before and after treatment. They found attitudes were generally positive toward DI at the outset. No systematic trends in anxiety were identified and no differences between women who became pregnant and those who continued treatment were recorded. Both pregnant and non-pregnant women acknowledged the strain involved in timing insemination to coincide with ovulation. They attributed the outcome to their psychological and emotional state at the time. These researchers recommended improved methods for detecting the fertile period to allay worries that insemination will not occur at the optimum time. They also believed that psychological preparation and counselling would alleviate some of these stresses.

Snowden et al. (1983) found that most couples preferred DI to adoption. The couples' major preoccupation was to ensure that people outside the medical profession would not discover they were receiving DI.

IVF and Embryo Transfer

Haseltine et al. (1985) ascertained that stress resulted from the demands of the IVF program, the surgery involved, and failure to become pregnant. The social worker played an important role in educating couples in the procedures during the initial contact and ongoing support and counselling.

Given et al. (1985) investigated differences between infertile couples who chose IVF and those who chose other medical treatments. Their findings from a sample of 29 women and 21 men in an IVF program, and 13 women and 12 men in other treatments, indicated that IVF subjects rated higher on characteristics of ambitiousness, creativity, and independence. The hypothesis that the IVF subjects would receive a higher rating on anxiety and associated symptomatology from the behaviour list was not supported. Both groups commented that their infertility problem was stressful.

Daniels (1989) found an apparent equal commitment to IVF by the 101 couples waiting for treatment at a New Zealand clinic. This researcher reported a need for more support and discussion concerning infertility and IVF. There was a clear indication that couples wished to have a social worker or counsellor available throughout the process. Also, couples tended to overestimate the success rate.

In Fagan et al.'s (1986) study, 19 individuals from among 45 couples accepted for an IVF program in 1984 experienced sexual dysfunction or a psychological disorder. Couples with sexual dysfunctions were more likely to have unexplained infertility; however, there was no basis for concluding that IVF participants have a higher incidence of sexual dysfunction and psychiatric disorders than the general population. The researchers recommended including psychological assessment of couples as a standard consultation procedure within the IVF program.

Many studies, including Stewart and Glazer (1986), Holmes and Tymstra (1987), Leiblum et al. (1987a and 1987b), de Zoeten et al. (1987), Mahlstedt et al. (1987), Baram et al. (1988), Callan and Hennessey (1988), Callan et al. (1988), and Mao and Wood (1984), looked at the expectations and coping of IVF participants. Generally, individuals were satisfied with their experiences and would consider IVF again, regardless of the stresses involved. Again and again, these researchers emphasized the importance of emotional support from medical staff, especially in dealing with often unrealistic success expectations and unsuccessful attempts. Patients also needed counselling and guidance in their decision making to continue or abandon the procedure and to get on with their lives or look to sources such as adoption.

Other Issues

Holmes and Tymstra (1987) investigated the experiences and opinions of Dutch women who had participated in IVF. They found that fewer fertile women than infertile women believed that a "child of one's own" was a right, and that government insurance ought to cover IVF. Fewer fertile than infertile women approved experiments with "spare" embryos or the implantation of donated embryos.

Donnell (1990) looked at the perception of illness in the prediction of psychological adjustment among infertile patients. The results supported a process of dynamic self-regulation in the development and effect of a patient's "representation" of her medical condition. The use of avoidance coping style had a significant role in the individual's perception of illness. This researcher found that perception of illness, coupled with the patient's perception of her own ability to control her treatment and eventual outcome, accounted for 70 percent of the variation in depression. In addition, a high proportion of variation anxiety (46 percent) was explained by perception of illness alone.

Ferber (1989) examined the psychological effects of previous infertility on a pregnancy. This researcher did not find that women who experienced infertility were more anxious or had more difficulty in adjusting to pregnancy than the control group. The study showed that women who conceived after infertility had a better attitude toward the pregnancy and their baby. This may be due to lessening distress and anxiety among infertile subjects after conception. The study concluded that the pertinent literature is marred by too much speculative, clinical data with little use of formal measurements and empirical techniques.

Rank 2 Articles

Articles that were editorial, prescriptive, or analytical or reviews of research were entered into the data base as Rank 2 documents. The prevalent themes were: (1) impact, (2) practitioner-patient relationship, (3) support, (4) ethics, and (5) feminist perspective.

Impact of Fertility Treatments

Wright et al. (1989) reviewed about 30 research projects to validate three hypotheses linking infertility and psychosocial distress. These researchers concluded that, on the whole, patients diagnosed and treated in infertility clinics show significantly higher levels of psychosocial distress than control groups. They also concluded that women experience more distress than men.

By extending the theories of Chodorow (1978) concerning the psychological reproduction of mothering by women in our society, Kaplan (1989) investigated the differences in intensity between male and female reactions to infertility. She concluded that the experience appears to be more painful and difficult for women. Kaplan wrote that, in addition to physical pain, women in our society experience the inability to achieve a

goal, social stigma, altered relationships, and life disruptions, and are denied the affective gratification for which most men do not have a strong need. In looking at various available treatments, the author highlighted the stress associated with failed treatment and unresolved infertility. Like many researchers, she advocated a more holistic and humane approach to infertility and its treatment.

Gavarini (1989) claimed that a state of emergency has been declared — that there is an epidemic of sterility — without yet being able to study the extent of the problem and its development. When objections are raised to medically assisted procreation on the grounds of psychological and financial cost, they are put aside in the name of women's wishes and consent. This writer believed these techniques become a panacea, granting all women the right to bear children. He stated that France is setting up (1989) a vast network of fertility centres, as in the United States, without knowing (1) how the level of need was determined, (2) how many patients will be treated at each centre, or (3) what definition of sterility will be used to determine the level of need for the service.

Practitioner-Patient Relationship

Van Hall (1985) wrote about the importance of the patient-doctor relationship. He viewed this relationship as unlike other forms of medical care in that the mutual goal of patient and physician is a social achievement. Because of the long period of infertility management, emotional and psychosocial factors can come into play, particularly concerning DI and IVF treatments. Van Hall advocated time lapses in order for pregnancies to occur without intervention. When pregnancies are not achieved after long, thorough investigations, the physician needs to overcome a personal sense of frustration and direct attention and energy to helping couples cope with their grief. This author believed the psychological stress during IVF cycles can be great and can affect the delicate mechanism of implantation; therefore, professional preparation of patients could improve pregnancy rates.

Chatel (1983) stated that the doctor's role in IVF goes beyond the medical procedure. The doctor permits the impregnation to go forward; therefore, the symbolic power of this action should not be underestimated.

Cabau and de Senarclens (1986) wrote:

When confronted with a situation of infertility, three human dimensions must be explored:

1. the attitudes or emotions of the women, or of the couple ...;
2. the counter-attitude and feelings of the doctor, which will determine the approach; and
3. the psychological climate which corresponds to the varied and changing interactions which take place between the doctor and the patient. (p. 667)

Christie and Pawson (1987) wrote about the need for a holistic approach to infertility treatment, recognizing that emotions may disturb the sensitive regulation of reproduction. For a healthy treatment outcome, they argued, the doctor must ensure that the process is a "learning and growth-promoting experience" for the couple, whether there is a baby or not. They recommended early interviews to uncover existing concerns and to develop a good relationship between physician and couple. Regarding the patient-doctor relationship, these authors highlighted the magnitude of the doctor's influence, which may cause a positive transference in the psychoanalytical sense; that is, where a woman may endow her physician with attributes drawn from her unconscious wish for an ideal parent image. They cautioned that too-intense positive or negative transference could interfere with treatment. The physician must be able to

... transcend the medical model, acquire a relationship perspective on the couple and view their problem in its psychosocial setting. In this he may well be aided by the psychoanalytically trained psychiatrist or psychologist. But he also needs to be able to transcend the psychoanalytic model, as this can tend to obscure psychosocial realities behind the drama of an individual's uncovered fantasies. (p. 337)

Taymor (1990) suggested that the fertility specialist should be the screening physician, practising preventive psychiatry and identifying patients with significant emotional conflicts for whom psychiatric consultations could be arranged. Taymor recommended psychiatric consultation for all patients with unexplained infertility.

Schinfeld et al. (1986) looked at the special responsibilities of the attending infertility specialist. This physician must master the sub-specialty's surgical and medical skills and understand the associated social, sexual, and ethical problems. Because the couple has lost control of their lives by failing to conceive, ethical issues are particularly sensitive in this specialty. Questions of when to refer or terminate the work-up and therapy involve ethical reflection about potential conflicts of interest. Blackwell et al. (1987) also warned about the special nature of infertility treatments. They were concerned that infertile couples may be "exploited" by a "malpractice crisis, which is forcing obstetricians into the subspecialty areas of gynecology without adequate training; ... the development of new technology, which often occurs in an ethical and regulatory vacuum; and ... the entrance of for-profit organizations into the infertility arena." (p. 735)

Spencer (1987) explored the notion that infertile couples experience stages of grief over their loss of potential life, and that these feelings are much the same as those experienced by persons grieving over death. Therefore, a physician sensitive to the psychological stresses these patients undergo during diagnosis and treatment can do much to prepare them for "what they may feel, moderate their reactions, and help them move on to acceptance."

Ruddick (1988) discussed two common sources of professional pressure: (1) "... (modern) physicians speak of their professional commitment to Respecting and Prolonging Life ... these abstract goals make medically assisted conception and fetal therapy ... commendable" (p. 74); and (2) when professional abstractions are powered by professional optimism, pressure on patients is even greater. "Optimists typically disregard probabilities of success, low or high; they are moved rather by *possibilities*, confident in their capacities to beat the odds." (p. 74)

Support Systems

Since infertility treatment may involve uncertainty, lack of control, and possible failure, Reading and Kerin (1989) made a strong case for a holistic approach to this medical practice. They believed specific ways of dealing with the psychosocial needs of infertile couples at all stages of treatment are necessary. It is not enough to focus on the reproductive organs or processes. They stated that early identification of psychological issues provides opportunities to intervene before these issues exact a toll.

Clément (1983) concluded that the pre-IVF psychological interview can be used to calm the couple's fears, dispose of their fantasies, and affirm them in their course.

Even though research highlighted the need for such services, Leader et al. (1984) claimed little systematic research had been devoted to determining the specific psychological needs of infertile persons or the effectiveness of current support systems in easing their emotional difficulties. These authors described such psychological assistance as "non-judgmental, empathetic and caring" — helping men and women to come to terms with their infertility. Bell (1983) believed: "The success of the clinic should be judged by its ability to maximise the quality of life of all its patients, not only by the pregnancy rate achieved." (p. 52)

In a review of DI literature, Edelmann (1989) concluded that much research to date had produced "inconclusive results and half-answers and allows for only tentative conclusions to be drawn." (p. 10) He advocated counselling for individuals considering DI so that they can arrive at the best decision — in effect, screening themselves. Counselling should continue beyond treatment in case of failure, and research has not addressed these needs. The cooperation of DI families is needed to further research in this field. As Edelmann wrote, this is difficult given the secrecy associated with DI.

Many writers, including Beck (1976), Rosenfeld and Mitchell (1979), Seibel and Levin (1987), Waltzer (1982), Mahlstedt and Greenfeld (1989), Greenfeld et al. (1986), Greenfeld and Haseltine (1986), Batterman (1985), Bombardieri and Clapp (1984), Needleman (1987), Berger (1977 and 1982), Dennerstein and Morse (1988), Notman (1984), and Sundby (1988), attended to the psychosocial aspects of infertility and its treatments. Each writer advised a psychosocial team to assist the fertility specialist in providing a holistic approach. Some writers dealt with the special role of

the social worker (Needleman, Batterman, and Greenfeld) as part of a support system, and others advocated mandatory counselling (Seibel and Levin). Waltzer, however, saw no justification for routine psychological or psychiatric examinations for couples requesting DI. On the other hand, Beck believed that proper preparation and counselling of DI couples "will go a long way in creating a climate that is favorable for success." Berger again highlighted the problem of secrecy around DI in any attempt to facilitate openness.

Ethics

Many writers, especially feminists, were concerned with the ethical implications of infertility treatments. Stotland (1985) was concerned with the introduction of machinery and technology into delicate human reproductive processes. She believed these intrusions can have complex psychological effects where science offers hope; yet, this hope may delay infertile individuals' resignation to unchangeable biological realities. She questioned the notion of "informed consent" when the procedure is new and there is as yet no knowledge of long-term consequences. She questioned where consumers' rights end and doctors' rights to govern their behaviour begin. She also wondered who shall be the gatekeeper for procedures too technical or expensive to be available to all and for those resulting in the end or beginning of human life.

Eichler (1989) raised some important questions about the use of new reproductive technologies as they pertain to "motherhood" and the role of sociologists. Some questions: What are the long-term consequences of having undergone intensive, unsuccessful infertility treatment? What are the long-term effects of heroic efforts on mothers, fathers, and children in cases of successful treatments? What has been the effect of preconception contracts for the production of children? What are the effects of anonymity of genetic parentage on offspring, and on recipients (and their spouses, where applicable)? What are the selection criteria for admission to various treatment programs at private clinics and hospitals? What information is conveyed to clients? What are the consequences of "donating" an egg on a "donor" (or vendor) and other affected parties? Which women volunteer eggs (if they do so) and why? Which men volunteer semen (if they do so) and why? Most important, what are the reasons for infertility? How much could be prevented?

Uniacke (1987) examined whether people have the right to reproduce. This writer claimed that "the severe, sometimes unrelievable anxiety and feelings of worthlessness derive from the view that having children is not simply a worthy avenue of personal development, but an essential good like life, health, and basic education." (p. 254) She did not believe this position is important to maintain or defend.

Simons (1984) asked regarding public funding of infertility treatment: "Must low-income couples remain childless because they lack the means to pay for proper care?" Another equity issue raised is the treatment of

single women for fertility problems or for infertility: "one must question the existence of a double standard whereby those paying out-of-pocket may obtain whatever procedures they can afford." (p. 67)

Within a sociological perspective, Novaes (1983) looked at French IVF practice. She wrote that the desire for children is governed in part by sociocultural beliefs. For instance, she considered IVF not a medical practice but a therapy conforming to social norms governing human biology and reproduction. Roles of father and doctor are redefined. She pointed out that if IVF were defined as a medical act, then the doctor would legally be responsible for the consequences.

Novaes (1983) stated that IVF challenges the family's reproductive autonomy. Reproductive capacity becomes a transmissible property, which the family may cede to another. The doctor, the donor, the sperm bank, and the intermediary become new controls able to offer or refuse the means to reproduce. Sperm banks offer a means of bypassing natural reproductive limits. Childbearing is no longer the sole and legitimate property of the heterosexual couple. Donating sperm is not a parental act, but a generous social act toward sterile couples. Also, the existence of sperm banks permits society to regulate infertility as a medical act apart from the couple's sexual life.

Hubbard (1980) argued that the push toward new reproductive technologies reinforces the stereotype that women's lives are unfulfilled unless they bear children. Why not try to change the practices that make it difficult for those desiring children to be linked with children needing parents? She believed that promising children to women by means of an untested technology, which is tested only as it is used, adds another wrong to the burdens of socialization. She suggested that a better solution should be found for women who want to parent and cannot bear children, especially in light of the cost of procedures such as IVF and other pressing social needs, including homeless children.

Achilles (1990) believed social policy lags behind the development of medical technologies. Discussion about new reproductive technologies must occur within the social context and consequences of reproduction and mothering. Isolated and unquestioned, technologies may reinforce "the traditional hopes and despairs of women as childbearers." Or, as McShane (1988) wrote, IVF has introduced a new era of genetic engineering "whose potential we have not yet begun to realize."

Chatel (1983) wrote that the decline in religiosity in Quebec contributes to couples' marginal concern about IVF's moral and religious aspects. Legal concerns over custody in case of separation or the sperm donor's "natural rights" cause more concern.

Daniels (1986) explored issues concerning new reproductive technologies research. This work highlighted the importance of recognizing who controls the research and where the power resides, setting up a program so that doctors are worked with rather than against, entering research from a firmly established, respected clinical base, clarifying

research aims and methodology, agreeing about the management of information obtained, using social work skills, and obtaining project endorsement from appropriate ethics committees.

Feminist Perspective

Rothman (1984) argued that choices are lost as technologies develop. "The individual right to choice is an absolute necessity, but not alone sufficient to ensure an ethics of reproduction." (p. 23) Rothman wrote that women know choice is based on information; however, she pointed out that power gives one control over information and choice. She felt strongly that new reproductive technologies empower and enslave, that they can all be used by, for, or against women. She concluded:

There will never be "free" choice, unstructured reproductive choice. But the structure in which choices are made should, and I believe ultimately can, be made fair, ethical, moral. Individual rights to information and to choice are an absolute necessity for such a system, but are not alone sufficient to ensure an ethics of reproduction. The next step in the politics of reproductive control is the politics of social control. (p. 33)

Rothman expressed concern about one of the negatives surrounding new choices for the infertile: the burden of not trying hard enough. She asked:

Just how many dangerous experimental drugs, just how many surgical procedures, just how many months — or is it years? — of compulsive temperature-taking and obsessive sex does it take before one can now give in gracefully? When has a couple "tried everything" and can finally stop? All of the technology still leaves many couples, about a third or more of those treated for infertility, without pregnancy. At what point is it simply not their fault, out of their control, inevitable, inexorable fate? (p. 31-32)

As Schuker (1988) stated,

My personal bias is toward minimizing social controls and maximizing voluntary choice in the application of these technologies. This is because I fear that advocates of social controls over others' decisions about their bodies and lives tend to be expressing their own prejudices and deep psychological needs and their own wishes to dominate and control others for their own purposes ... Whether the woman is older or younger, I feel that each individual must make the choice ... in an environment that provides educational information, psychological support, and the best available medical skills. (p. 146)

Lorber (1988) took the position that, because couples are involved, infertility is a social problem. Writing about IVF, she stated that the procedure is not "new," but there is an increased public awareness about and demand for infertility treatments. Sometimes patients' concerns and hesitations are ignored or discounted. She also stated that, in our society, men often are the dominant partners; therefore, they tend to dominate

reproductive decisions. She concluded that women are not necessarily victims; however, she believed they are not entirely autonomous.

The dynamics of participation in such treatment illuminates issues of men's domination in reproduction and the extent to which women can truly control their bodies when faced with personal, psychological, familial, and community pressures to produce a biological child. (p. 126)

Warren (1988) believed that little public and professional debate on new reproductive technologies, such as IVF, has focussed on their possible negative effects on women and resulting children. She stated that, with the exception of a few feminist critics, little concern has been advanced for the dangers to women who "serve as experimental subjects in reproductive research." (p. 37) She recommended that women should make up half of all governing regulatory bodies, all ethics committees, and all public agencies funding reproductive research to ensure that women's concerns are heard. Another recommendation was for better dissemination of information about preventing infertility.

Since new reproductive technologies deal directly with female bodies, change social relations between sexes, change the concepts of maternity and paternity, and open the door to human genetic engineering, Bryant (1990) and Koch and Morgall (1987) were concerned for a feminist assessment of these technologies. Koch and Morgall highlighted problems concerning ethics and legalities, social implications, social roles and conceptions, and economics. They were particularly concerned that these technological advances should be seen as the medicalization of the female body by a male-dominated medical hierarchy, which holds much social power and prestige and can define what a "normal" woman is.

We call for an increased effort to develop methods and theories in the new discipline of feminist technology assessment based on the interests and experiences of women. (p. 190)

Murphy (1984) was concerned about women's control of their own bodies and likened the IVF procedure to "egg farming." She made a direct connection to the possession of eggs and what is female, feeling strongly that if women lose control of the release, fertilization, and reimplantation of their eggs, they will be exploited for patriarchal ends. She wrote: "... since the egg farming of women's bodies currently exists within patriarchy, and is carried out for patriarchal ends, we must establish control over our eggs. We must challenge egg farming by establishing our bodies as other than 'reproductive bodies.'" (p. 74)

Hornstein (1984) and Klein (1984) reported on alternative DI programs. These programs allow women to control their own reproductive capacities without a male sexual partner. Hornstein wrote about feminist clinics that make sperm donors available to women based solely on their choice and decision. Klein told about women forming self-insemination families, where

the emphasis is not on "one parent-one child," but on the inter-relationships of mothers and their children.

Ruddick (1988) wrote:

Whatever the moral and metaphysical complexities of reproductive decisions, the answer to "Who should decide?" is clear. Women, and only women, should make decisions about their own childbearing. This does not exclude the concerns of men they care for, or the advice of men they trust. But it does exclude men, publicly or privately from having a veto or decisive voice in questions about the number, timing, or aborting of pregnancies, or the method of conception — or, the question of adoption versus conception. (p. 73)

4. Conclusion

Of issues raised in this review, none received as much attention as those of the emotional factors endured by participants in infertility treatments, and the need for psychological support for people considering, undergoing, or ending treatments. Factors such as anxiety, worry, fear, doubt, concern, disruption, change in relationships, loss of self-esteem, guilt, depression, and isolation were documented repeatedly. Significantly, when male and female experiences were compared, women bore the most stress related to diagnosis and treatment as well as the most physical pain. It may be concluded that the psychological strain of infertility treatments is greater for women. For men, issues such as the redefinition of paternity in DI cases or psychological factors concerning the diagnosis of infertility have an impact on their lives; however, the decision making, treatment, and resolution of unsuccessful attempts are less traumatic for male participants than for their female partners. Because of the emotional costs to infertile individuals who undergo treatments, most researchers and writers recommended psychological support for these people — before, during, and after ending treatment.

Perhaps a new profession will emerge — management of the psychological aspects of infertility treatment. For instance, it was suggested that more attention should be given to the psychological aspects of ET, and that adequate psychological preparation of the female patients could improve post-IVF pregnancy rates. As some researchers concluded, the environment in which treatment takes place, rather than the treatment itself, might cause extra stress and possible anovulation. In that several studies and articles emphasized the stress factors involved, more controlled studies need to be undertaken to identify effective stress-management programs. Wherever possible, attempts should be made to relieve participants' worry. One researcher recommended improvements to the methods for detecting fertile periods, so that insemination will occur at the optimum time.

The timing of the psychological support for the individual or couple is important. Some researchers documented the effectiveness of the first interview for those considering treatment to deal with questions, fears, fantasies, and sometimes unrealistic hopes for outcomes. Others recognized the importance of support after each treatment, while the patient awaits the results. There is also need for psychological help if infertility treatments fail — especially after long periods. There was an expressed interest in follow-up studies of individuals who continue treatment for long periods versus those who end the program. Perhaps the ongoing research of Andrews et al. (1991) will address these concerns.

Several authors emphasized the need for more holistic management of treatment programs. It was recommended that the doctor and infertile couple or individual should be supported psychologically in a non-judgmental, caring system by staff knowledgeable of various treatments and their accompanying emotional factors. Several writers advocated an interdisciplinary team approach, where specialist and patient are assisted in the procedures' emotional and physical demands.

There was an overwhelming appeal for a more compassionate, understanding relationship between medical specialists and infertile couples or individuals. This appeal was for an awareness by the specialist of his/her own motivations and control/ego needs in the medical procedures and outcomes. The decision to proceed, delay, or end treatments often is made by these specialists. Advocates appealed for doctors who are concerned equally about the psychosocial implications of the treatment and its physical component. There was much concern among feminist thinkers and writers that new reproductive technologies medicalize women's rights to make choices and govern their own bodies. Because the medical profession is still dominated by men, some writers worried that women's decision making will be dominated by male perspectives and agendas.

Attention was given to what is implied in the decision-making process and what constitutes "informed consent" regarding use of new reproductive technologies. There was concern in the literature as to how decisions are made, whether there really is a choice, and, most important, whether this choice is within the decision maker's power. Infertile people experience pressures from within, from their community of friends and family, and from society, which may transmit the message that a woman who cannot conceive is a lesser person. Again, some writers believed informed choice is a process whereby individuals have all necessary information, help, and power to determine what is best for them.

The literature seemed to indicate that concern must be directed at viable treatments and at healthy outcomes (both psychological and physical) for the infertile, whether there is a child or not. Because clinics seem to deal more with infertility than with its prevention, some writers and researchers believed more attention should be given to prevention rather

than cures. Others were concerned about access to treatments and who is being turned away and why.

There was debate in the literature about whether having a biological child is a human right, or whether infertility is an illness needing a cure. Social policy lags behind these rapidly developing medical advances. As new reproductive technologies become more sophisticated, the social dilemmas posed by them become more complex. Out of concern for the lack of sound research findings, and the experimental nature of many infertility treatments, many researchers and writers believed that better research, in the form of longitudinal studies, is needed to define the psychosocial impact of procedures and reactions to treatment outcomes. Because studies often are uncontrolled, with inconstant patient populations, small sample sizes, and inconsistency in the definition of success, it is often difficult to compare results. In the area of psychosocial implications of infertility treatments, there seemed to be a need for carefully conducted studies directed toward key areas: longitudinal studies on the effectiveness of various technologies; the male infertility factor; and long-term effects of new reproductive technologies on society, women, men, family, children, and public health. First, the public and professionals must agree about the values on which research will be based.

Feminist writers brought attention to the negative effects of infertility treatments and requested a feminist-oriented assessment of new reproductive technologies. They noted repeatedly that new reproductive technologies are used on women's bodies; thus, women should control their use and legislation. There was a call for a redefinition of social roles, maternity, and paternity. Writers cautioned about changes created by these technologies, with respect to the human body and social values. Concerning possible negative effects of new reproductive technologies on women, feminists recommended more debate among an informed public, professionals, and users of treatments.

After examining more than 180 documents, the reviewer is impressed not by treatment successes, but by the larger percentage of "failures." More attention must be given to the women who keep trying and must cope with disappointment over long periods. What, if any, is the psychosocial fall-out for this group? What happens to their marital relationships, their self-esteem, their self-worth, and, at times, their physical well-being? An interesting study would compare women who keep trying, women who succeed, and women who end their treatments.

The jigsaw puzzle is complete, and the picture is not encouraging. More controlled longitudinal studies are needed to better assess the psychosocial implications of infertility treatments and make recommendations for individuals and society. Meanwhile, a more holistic approach to treatment may relieve some emotional stresses endured by participants, especially women.

Appendix 1. Tests Used in Rank 1 Studies

Depression

Beck, A.T., et al. 1961.

"An Inventory for Measuring Depression." *Archives of General Psychiatry* 4: 561-71.

Lubin, B. 1981.

Depression Adjective Check Lists: Manual. San Diego: Educational and Industrial Testing Service.

Parental Behaviour

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"Opening the Safe: A Study of Child-Focused Families." In *Systems Therapy — Selected Papers: Theory, Technique, Research*. Washington, DC: Groome Child Guidance Center.

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The Child Abuse Potential Inventory: Manual. 2d ed. Webster: Psytec.

Parker, G. 1983.

Parental Overprotection: A Risk Factor in Psychosocial Development. New York: Grune & Stratton.

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"The Predictive Questionnaire: A Preliminary Report." In *Helping the Battered Child and His Family*, ed. C.H. Kempe and R.E. Helfer. Philadelphia: J.B. Lippincott.

Personality

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An M.M.P.I. Handbook: A Guide to Use in Clinical Practice and Research. Minneapolis: University of Minnesota Press.

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Minnesota Multiphasic Personality Inventory: User's Guide for the Minnesota Report. Minneapolis: University of Minnesota, MMPI.

Krug, S.E., and R.B. Cattell. 1971.
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Sweetland, R.C., and D.J. Keyser, eds. 1986.
Tests: A Comprehensive Reference for Assessments in Psychology, Education, and Business. 2d ed. Kansas City: Test Corporation of America.

Psychiatric

American Psychiatric Association. 1980.
Diagnostic and Statistical Manual of Mental Disorders. 3d ed. Washington, DC: American Psychiatric Association.

American Psychiatric Association. 1987.
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Loevinger, J., and R. Wessler. 1970.
Measuring Ego Development, Vol. 1 and Vol. 2. San Francisco: Jossey-Bass.

Snaith, R.P., G.W.K. Bridge, and M. Hamilton. 1976.
"The Leeds Scales for the Self-Assessment of Anxiety and Depression." *British Journal of Psychiatry* 128: 156-65.

Spitzer, R.L. 1975.
Schedule for Affective Disorders and Schizophrenia. 2d ed. New York: New York State Psychiatric Institute, Biometrics Research.

Weissman, M.M., and S. Bothwell. 1976.
"Assessment of Social Adjustment by Patient Self-Report." *Archives of General Psychiatry* 33: 1111-15.

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SCL-90: Administration, Scoring and Procedures. Manual for the Revised Version. Baltimore: Johns Hopkins School of Medicine, Clinical Psychometric Research.

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Rotter, J.B. 1966.

"Generalized Expectancies for Internal versus External Control of Reinforcement." *Psychological Monographs: General and Applied* 80: 1-28. Washington, DC: American Psychological Association.

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"Conjoint Marital Therapy: A Controlled Outcome Study." *Psychological Medicine* 8: 623-36.
- Kimmel, D., and F. van der Veen. 1974.
"Factors of Marital Adjustment in Locke's Marital Adjustment Test." *Journal of Marriage and the Family* 36: 57-63.
- Locke, H.J., and K.M. Wallace. 1959.
"Short Marital-Adjustment and Prediction Tests: Their Reliability and Validity." *Marriage and Family Living* 21: 251-55.
- Spanier, G.B. 1976.
"Measuring Dyadic Adjustment: New Scales for Assessing the Quality of Marriage and Similar Dyads." *Journal of Marriage and the Family* 38: 15-28.

Sex Roles

Bem, S.L. 1981.

Bem Sex-Role Inventory: Professional Manual. Palo Alto: Consulting Psychologists Press.

Spence, J.T., and R.L. Helmreich. 1978.

Masculinity & Femininity: Their Psychological Dimensions, Correlates, & Antecedents. Austin: University of Texas Press.

Sexual Functioning

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The Sexual Experiences Scale (S.E.S.) Manual. Amsterdam: Swets en Zeitlinger Testing Service.

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Appendix 2. Analysis of Standardized Tests Used in Three Rank 1 Studies

This analysis was prepared to indicate the kinds of standardized tests used in research on the psychosocial implications of infertility treatment.

The three studies analyzed were chosen from among the Rank 1 documents summarized in this report. All focussed narrowly on the psychosocial implications of infertility treatment and relied on instruments commonly used in similar studies and, therefore, thought to be easily accessible.

Locating the primary sources for many instruments proved difficult, however, given time and budgetary constraints. Few manuals or source articles were available through libraries or resource centres.

The information contained in this appendix was taken from the three Rank 1 studies, primary source materials (such as manuals or published papers on the instruments), and reference texts. A brief description of the methodology and sample used is provided. Information on each instrument used in a study is organized under the following headings:

- a. article notes;
- b. description from primary source; and
- c. notes from other sources (specified in each case).

The analyzed studies were:

1. Leiblum et al. 1987;
2. Harrison et al. 1981; and

3. Harris. 1989.

The Leiblum et al. (1987) Study

Description

This pilot study identified and determined the psychological and physical concomitants of the various phases of IVF and assessed the reactions of wives and husbands throughout and following one or more IVF cycles.

The sample included 59 couples who completed at least one cycle of IVF and returned both pre- and post-IVF evaluation questionnaires. A total of 158 pre-IVF questionnaires were collected.

The pre-IVF questionnaire assessed relevant demographic and background information. Participants also completed three standardized questionnaires (described below). Five weeks after beginning IVF, a post-IVF questionnaire assessed the overall stress of the procedure and reactions to menotropin drugs, ovum transfer, feelings toward transfer, feelings following transfer, and the resumption of menses. Couples also completed two questionnaires again (MAT and POMS).

Instruments

1. Locke and Wallace. 1959.
 - a. Article notes:
 - The instrument was applied in an unaltered form.
 - b. Description of the instrument from primary source:
 - "Marital adjustment" refers to the accommodation of husband and wife to each other at a given time; "marital prediction" refers to the future likelihood of marital adjustment.
 - The source article examines the hypothesis that reliable, valid adjustment and prediction tests can be constructed using a limited number of the most significant items taken from earlier studies (1929-1951).
 - Fifteen items were taken from previously developed adjustment tests and 35 from prediction tests. (A list of these items is provided in the source article.)
 - The test was applied to a sample of 118 husbands and 118 wives (not married to each other); the sample was predominantly young, white, educated, Protestant, white-collar, professional, and urban.
 - The reliability coefficient of the adjustment test was .90; a comparison of mean adjustment scores with extensive case data illustrated the validity of the test (i.e., it tested what it was meant to test).

- The reliability coefficient of the prediction test was .84; prediction scores were correlated with adjustment scores to examine validity (since longitudinal studies were impossible) and the coefficient of correlation was .47 (comparable with other tests).
2. McNair et al. 1971.
- a. Article notes:
- POMS is a 65-item, five-point adjective rating scale. Respondents read a list of adjectives describing various mood states and rate each one in terms of "How have you been feeling in the past week, including today?"
 - Six POMS factors are scored: tension-anxiety, depression-dejection, anger-hostility, vigour-activity, fatigue-inertia, and confusion-bewilderment.
- b. Description from primary source:
- Unavailable.
3. Rotter. 1966.
- a. Article notes:
- A 23-item scale (plus six filler items) that assesses beliefs about whether one's own actions have an impact on what happens in the world (the higher the score, the greater the belief in externality, that is, in fate, luck, or chance).
- b. Description from primary source:
- Unavailable.
- c. Notes from other sources:
- From Harris (1989).
 - A 29-item forced-choice scale with "reasonably high internal consistency;" "test-retest reliability is satisfactory;" "the most significant evidence of the construct validity of the I-E scale comes from predicted differences in behavior for individuals above and below the median of the scale or from correlations with behavioral criteria." (Comments from Rotter 1966, 25.)
 - Because items on the I-E scale are not comparable, split-half reliability measures do not adequately demonstrate the internal consistency of the scale.
 - For female college students, the Kuder-Richardson was .76. Test-retest reliability was .83 in the same study.

The Harrison et al. (1981) Study

Description

Infertility investigations and treatment are stressful for couples; however, they are particularly stressful for women undergoing DI and homologous AI. The stress may give rise to anovulation, which has led some inseminators routinely to use agents such as clomiphene citrate to ensure normal cycling. This study examined the extent of the problem, whether it is predictable, possible reasons for it, and whether existing therapy is apt and adequate.

The sample comprised 30 women attending DI because their husbands had azoospermia. The clinical controls were 10 consecutive couples with psychosexual problems practising AI at home. Psychological controls were eight fertile couples who underwent the same psychological studies as 10 of the DI patients.

The women undergoing DI were followed throughout their therapy. They were reviewed monthly for a year. If anovulation developed, clomiphene citrate was prescribed. The last 10 of these patients underwent psychological assessment before starting therapy. Four tests were used (described below).

Instruments

1. Spielberger et al. 1970.

a. Article notes:

- The instrument was applied in an unaltered form.

b. Description from primary source:

- Unavailable.

c. Notes from other sources:

- From Harris (1989). (*These notes refer to a later version of STAI, 1983.*)
- STAI is a self-report inventory with two sets of 20 statements measuring state and trait anxiety.
- Test-retest reliability correlations for the Trait Anxiety Scale ranged from .73 to .86 for college students; the State Anxiety Scale had a test-retest reliability of only .16 to .62 (consistent with the fact that the scale is supposed to be sensitive to situational factors).
- The internal consistency measure of this scale provides a better measure of its reliability; all but one of the alpha coefficients for the Form Y S-Anxiety are above .90. Similar coefficients found for the T-Anxiety Scale (median coefficient of .90).

- Concurrent validity for the original Form X T-Anxiety Scale are reported to be .73 to .85 when correlated with the Institute for Personality and Ability Testing (IPAT) Anxiety Scale and Taylor Manifest Anxiety Scale.
- Construct validity has been evidenced for the T-Anxiety scale by comparing mean scores of normal subjects with mean scores of neuropsychiatric patients, as well as comparing the T-Anxiety scores of surgical patients with psychiatric problems against those of surgical patients with no such history.
- The S-Anxiety Scale was administered to military recruits after a highly stressful activity, and their scores were correlated with those of college and high school students tested under low stress conditions.

2. Taylor. 1953.

a. Article notes:

- The instrument was applied in an unaltered form.

b. Description of the instrument from primary source:

- A manifest anxiety scale, consisting of items drawn from the MMPI judged by clinicians to be indicative of manifest anxiety, was developed as a device for selecting subjects for experiments in human motivation. The current test was administered to 1971 students in introductory psychology at the State University of Iowa during five successive semesters from September 1948 to June 1951.
- After statistical analysis, the original 65-item scale was reduced to the 50 most discriminating statements. These items, supplemented with 225 statements non-indicative of anxiety, are administered under the title Biographical Inventory.
- In one instance, the results of retesting 59 students after a three-week lapse yielded a Pearson product-moment coefficient of .89; in a second test-retest study, the coefficient was found to be .82 over five months and .81 for periods of 9 to 17 months.
- For all groups tested, both the relative position of the individual in the group and her/his absolute score tended to remain constant over relatively long periods.
- Relationship of the Biographical Inventory to the MMPI: discrepancies in the results of the inventory and the MMPI suggest that a radical change in filler items may influence anxiety scores.
- A further scale revision was undertaken in which certain items were rewritten to simplify vocabulary and sentence structure;

characteristics of the revised version were found to be similar to those of the previous form.

- To determine the relationship between the anxiety-scale scores and manifest anxiety as defined and observed by the clinician, the anxiety scores for groups of normal individuals and psychiatric patients were compared. Results suggest a relationship between the anxiety-scale scores and clinical observation of manifest anxiety.

3. Cattell et al. 1970.

a. Article notes:

- Only the anxiety factor was measured using this instrument.

b. Description from primary source:

- Unavailable.

4. Eysenck and Eysenck. 1975.

a. Article notes:

- Only the neuroticism factor and lie score were measured using this instrument (Eysenck Personality Inventory).

b. Description from primary source:

- Unavailable.

c. Notes from other sources:

- From Sweetland and Keyser (1986), *Tests: A Comprehensive Reference for Assessments in Psychology, Education, and Business*. (Reference book containing a brief description of a later version of the test)
- The Eysenck Personality Inventory measures extroversion and neuroticism, the two personality dimensions that account for most personality variance. It is used for counselling, clinical evaluation, and research.
- The questionnaire is a 57-item, paper-and-pencil, yes-no inventory measuring two independent dimensions of personality, extroversion-introversion and neuroticism-stability. A falsification scale detects response distortion. It is available in equivalent forms A and B for pre- and post-testing and in Industrial Form A-1. College norms are presented in percentile form for forms A and B, both separately and combined. Adults norms are presented for Form A-1.

The Harris (1989) Study

Description

The study tested the theory that infertility diagnosis and treatment is a crisis during which women demonstrate more emotional problems and sex-role conflict, and report less marital satisfaction, than women who have terminated treatment.

The sample consisted of 52 infertile, Caucasian, married women aged 24-42. The subjects were administered seven self-report measures (described below).

Instruments

1. Spielberger. 1983.

a. Article notes:

- STAI is a self-report inventory with two sets of 20 statements measuring state and trait anxiety.
- Test-retest reliability correlations for the Trait Anxiety Scale ranged from .73 to .86 for college students; the State Anxiety Scale has a test-retest reliability of only .16 to .62 (consistent with the fact that the scale is supposed to be sensitive to situational factors).
- The scale's internal consistency measure provides a better measure of its reliability; all but one alpha coefficient for the Form Y S-Anxiety are above .90. Similar coefficients were found for the T-Anxiety scale (median coefficient of .90).
- Concurrent validity for the original form X T-Anxiety scale are reported to be .73 to .85 when correlated with the IPAT Anxiety Scale and Taylor Manifest Anxiety Scale.
- Construct validity has been evidenced for the T-Anxiety scale by comparing mean scores of normal subjects with mean scores of neuropsychiatric patients, and comparing the T-Anxiety scores of surgical patients with psychiatric problems with those of surgical patients with no such history.
- The S-Anxiety scale was administered to measured military recruits after a highly stressful activity and their scores were correlated with those of college and high school students tested under low-stress conditions.

b. Description from primary source:

- Unavailable.

2. Lubin. 1981.

a. Article notes:

- A self-report adjective checklist (the DACL) consisting of 32 or 34 adjectives that the respondent must check if applicable.
- For assessment of state depression, a person checks words that describe "how you feel now — today;" for this research, the individuals were instructed to check the words that described "how you have been feeling recently;" Form E was administered to assess state depression.
- All seven forms of the DACL correlate with one another at the .01 level of significance (with correlations of .80 to .93).
- Internal test consistency is .79 to .90; overall reliabilities are .82 to .93 for normal populations.
- Test-retest reliability for the state form of the DACL is low, demonstrating its sensitivity to mood changes.
- Concurrent reliability has been demonstrated by correlating the DACL with the Multiple Affect Adjective Check List depression scale. In addition, the DACL has correlated positively with self-ratings of depression, judges' ratings of depression, and state and trait measures of depression.
- In the new trait form of the DACL, forms E, F, and G are used. Directions change from a "today" focus to "how you generally feel." Norms have been gathered on these forms for three years with male and female college students aged 25-50 years. Preliminary data analysis indicated the trait form is "even more reliable than the state version and predicts better" (Lubin, personal communication, 15 May 1987).
- This study assessed state depression using Form G, with instructions to "check the words which describe how you have generally felt in life."

b. Description from primary source:

- Unavailable.

3. Rotter. 1966.

c. Article notes:

- A 29-item, forced-choice scale (the I-E scale) with "reasonably high internal consistency;" "test-retest reliability is satisfactory." "The most significant evidence of the construct validity of the I-E scale comes from predicted differences in behaviour for individuals above and below the median of the scale or from correlations with behavioural criteria." (Comments from Rotter 1966, 25.)

- Because items on the I-E scale are not comparable, split-half reliability measures do not adequately demonstrate the scale's internal consistency.
 - For female college students, the Kuder-Richardson was .76. Test-retest reliability was .83 in the same study.
- d. Description from primary source:
- Unavailable.
4. Spence and Helmreich. 1978. (PAQ — Short Form)
- a. Article notes:
- There are no good definitions of masculinity and femininity among the many instruments developed to assess these characteristics.
 - The authors acknowledged that their test labels "masculinity" and "femininity" are actually "instrumentality" and "expressiveness."
 - The questionnaire assesses masculinity and femininity with a self-rating scale including male-valued items, female-valued items, and sex-specific items.
 - Three scale scores: M score, F score, and MF score (a measure of emotional vulnerability).
 - The original PAQ had a test-retest reliability for women of .91 on the Self-Rating scale and .98 on the Stereotype scale.
 - Correlations of .73 for women on the Masculinity subscale and .59 for women on the Femininity subscale were reported when the PAQ were correlated with the Bem Sex Role Inventory.
 - Other evidence of validity regarding the Stereotype scale: PAQ items had been used in prior research conducted with the Sex Role Stereotype Questionnaire.
 - This study's PAQ short form comprises eight items from each subscale of the long form, for a total of 24 items; the short form correlates with the long form on each of the three subscales at the .90 level.
- b. Description of the instrument from primary source:
- The primary source is a journal article describing a study undertaken to determine the instrument's accuracy.
 - A battery of tests was applied to a sample of high school students; these consisted of a Family Information Sheet and six objective questionnaires: (1) the Personal Attitudes Questionnaire, (2) the Texas Social Behavior Inventory, (3) the

Work and Family Orientation Questionnaire, (4) the Attitudes toward Women Scale, (5) the Parental Attributes Questionnaire, and (6) the Parental Attitudes Questionnaire.

- The short version of the PAQ was used in the study. It consisted of 24 bipolar items describing personal characteristics about which respondents rated themselves on a five-point scale. It is divided into three eight-item scales, Masculinity, Femininity, and Masculinity-Femininity.
- The full version of the PAQ contains 55 bipolar items drawn from a pool of more than 130 items, largely compiled from nominations by college students of characteristics differentiating men and women. The investigators' primary purpose was to demonstrate the existence of "sex-role stereotypes." The 55 PAQ items were drawn from among those about which both sexes exhibited a consistent stereotype, that is, it comprises items describing characteristics commonly believed to differentiate the sexes on in terms of which men and women tend to report themselves differing.

5. Sarason et al. 1978.

a. Article notes:

- The Life Experiences Survey (LES) is a self-reporting survey of 57 items. Subjects are asked to indicate life events from the past year.
- Only Section 1 of the LES was used because it contains items that might be typical of the general public. Section 2 items relate specifically to student populations.
- Subjects indicated the positive or negative impact of life events by checking a seven-point Likert scale, ranging from -3 to +3.
- For purposes of this study, only the negative change score was computed, since previous studies indicated that negative change has a more significant impact on health than positive change.
- Test-retest Pearson product-moment correlations for the negative change score were .56 ($p < .001$) and .88 ($p < .001$) when undergraduate psychology students were tested at five- and six-week intervals. This suggests that the LES is moderately reliable for the negative change score.
- The negative change score of the LES correlates positively at the .01 level with measures of trait anxiety and at the .001 level with measures of state anxiety.
- The negative change score demonstrably correlates with the Beck Depression Inventory and the Locus of Control Scale.

6. Locke and Wallace. 1959.

a. Article notes:

- The information contained in the thesis is drawn directly from the primary source; no test revisions were noted.

b. Description of the instrument from primary source:

- "Marital adjustment" refers to the accommodation of husband and wife to each other at a given time; "marital prediction" refers to the likelihood of future marital adjustment.
- The hypothesis examined in the source article was that reliable, valid adjustment and prediction tests can be constructed using a limited number of the most significant items taken from earlier studies (1929-1951).
- Fifteen items from previously developed adjustment tests and 35 from prediction tests.
- Test used on a sample of 118 husbands and 118 wives (not married to each another); sample was predominantly young, white, educated, Protestant, white-collar, professional, and urban.
- Reliability coefficient of adjustment test was .90; a comparison of mean adjustment scores with extensive case data illustrated the test validity (i.e., it tested what it was meant to test).
- Reliability coefficient of prediction test was .84; prediction scores were correlated with adjustment scores to examine validity (since longitudinal studies not possible) and the coefficient of correlation was .47 (comparable to other tests).

7. Cox. 1986. (Marital Closeness and Intimacy of Communication Interview.)

a. Article notes:

- The Marital Closeness and Intimacy of Communication interviews were excerpted from the *Measurement of Marital Relations Manual*.
- The Marital Closeness section is rated on a Likert-like scale ranging from very close (1) to very distant (5). The Intimacy of Communication questions are rated on a similar scale, from little or no intimacy (1) to great intimacy (5).
- In addition, a more open-ended section was added to the end of each interview, focussing on the experience of infertility treatment.

b. Descriptions from primary source:

- Unavailable.

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* The left-hand margin code is as follows: 1 - Rank 1 document; 2 - Rank 2 document; 3 - Rank 3 document; 0 - other; T - test study.

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* Dr. Andrews passed away in December 1992.

Mandate

(approved by Her Excellency the Governor General
on the 25th day of October, 1989)

The Committee of the Privy Council, on the recommendation of the Prime Minister, advise that a Commission do issue under Part I of the Inquiries Act and under the Great Seal of Canada appointing The Royal Commission on New Reproductive Technologies to inquire into and report on current and potential medical and scientific developments related to new reproductive technologies, considering in particular their social, ethical, health, research, legal and economic implications and the public interest, recommending what policies and safeguards should be applied, and examining in particular,

- (a) implications of new reproductive technologies for women's reproductive health and well-being;
- (b) the causes, treatment and prevention of male and female infertility;
- (c) reversals of sterilization procedures, artificial insemination, *in vitro* fertilization, embryo transfers, prenatal screening and diagnostic techniques, genetic manipulation and therapeutic interventions to correct genetic anomalies, sex selection techniques, embryo experimentation and fetal tissue transplants;
- (d) social and legal arrangements, such as surrogate childbearing, judicial interventions during gestation and birth, and "ownership" of ova, sperm, embryos and fetal tissue;
- (e) the status and rights of people using or contributing to reproductive services, such as access to procedures, "rights" to parenthood, informed consent, status of gamete donors and confidentiality, and the impact of these services on all concerned parties, particularly the children; and
- (f) the economic ramifications of these technologies, such as the commercial marketing of ova, sperm and embryos, the application of patent law, and the funding of research and procedures including infertility treatment.

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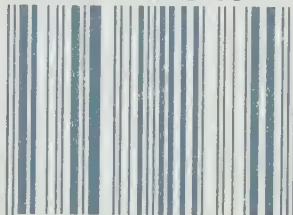
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